TITLE
Should the rights of the donor-conceived-offspring be the ruling bioethical principle of the disclosure of information regarding gamete donation in the UK?

AUTHOR
Hewitt, Alice

DATE DEPOSITED
16 November 2015

Should the rights of the donor-conceived-offspring be the ruling bioethical principle of the disclosure of information regarding gamete donation in the UK?

Alice Hewitt

MA Bioethics and Medical Law

St Marys University

2015

SMUC MA Bioethics and Medical Law
Dissertation BML7013
Regnum 125498

Contents

Acknowledgements

I would like to thank my supervisor, Matthew James, for all of his continued and unswerving support, advice and encouragement in writing this dissertation.

I am also grateful to Dr Trevor Stammers, for helping me to develop the original idea and for his help and guidance along the way.

I would also like to express my gratitude to Janet and Rodney Taylor, Nicola Haupt and Lucy Jones for all their comments, advice and support, and for their invaluable skills as proof readers.

Abstract

The Human Fertilisation and Embryology (Disclosure of Donor Information) Regulations 2004 removed the right of gamete donors to anonymity and gave donor-conceived-offspring a legal right to identify, and possibly contact, their donors on reaching the age of 18. The legislation was introduced because it was believed that donor-conceived-offspring have a right to information about themselves, including their genetic identity, and that denying them this information is harmful.

During the consultation period prior to this legislation being introduced considerable emphasis was placed on the interests, needs and rights of the donor-conceived-offspring to access their genetic identity, and potentially contact their donors and donor-siblings. Whilst this is understandable, far less attention has been paid to the interests, needs and rights of the donors, recipient parents and their respective families.

The potential impact of open-identity legislation on these other parties is huge, extending from the impact on donation numbers through to the psychological effect of discovering previously unknown family members. Despite this, they have been largely overlooked and their interests and rights subordinated to those of the donor-conceived-offspring with seemingly little discussion.

The donor-conceived-offspring, donors, recipient parents and their wider families exist as 'spider-web' families, held together by complex genetic, legal and social links.

Exercising the interests and rights of each member of the spider-web family has an effect on the other members of the family; the interests and rights of each must be balanced against each other to determine whose interests and rights take precedence.

By exploring the bioethical and legal rights of the donor, donor-conceived-offspring and their respective families following the introduction of the Disclosure of Donor Information Regulations 2004, this dissertation examines whether the rights of the donor-conceived-offspring should be the ruling bioethical principle regarding the disclosure of donor information in the UK.

Chapter One: Gamete Donation in the UK

A History of donation

Successful artificial insemination in humans is reported to have occurred first in 1785 (Agarwal 2007 p539) but it did not enter clinical practice in England until the late 1930s, when it was generally carried out in secret. In 1945, the publication of gynaecologist Mary Barton's article in the British Medical Journal (Barton et al 1945 pp.40-43) describing her artificial insemination (AI) programme was met with outrage and the practice was publically condemned. Despite this, it continued and in 1960 the Feversham Committee concluded that, while it should generally be discouraged, AI might be an acceptable treatment for some infertile couples (BMJ 1960 p379). Demand grew and in 1968 it became available on the NHS, if recommended on medical grounds (Warnock 1984 p19).

Although now legal, AI was unregulated and remained a covert practice. Until 1977 the donor-conceived-offspring (DCO) was illegitimate and the donor considered the legal father (Births and Deaths Registration Act 1954). The husband/partner of the woman receiving treatment had no legal responsibilities or duties toward the DCO, although in practice he was usually entered as the father on the birth certificate. This involved the couple in committing an offence by entering false information on the birth certificate but maintained the donor's anonymity, gave the husband/partner parental rights and

protected the family from public scrutiny and disapproval. Alternatively, the couple could adopt the DCO (Smart 1987 cited in Lycett et al 2005 p810).

The publication of the Warnock Committee report in 1984 changed this. The Committee was established in 1982 “to consider recent and potential developments in medicine and science related to human fertilisation and embryology; to consider what policies and safeguards should be applied, including consideration of the social, ethical, and legal implications of these developments; and to make recommendations." (HFEA 2014(b)). The Committee supported the use of donated gametes in fertility treatment and also recommended a change to the law so that “The AID [artificial insemination by donor] child should in law be treated as the legitimate child of its mother and her husband, where they have both consented to treatment” (Warnock 1984 p85). In 1987, the Family Law Reform Act (1987 Part 4) allowed the husband of the woman to be legally entered as the father on the birth certificate of the DCO (provided he consented to the treatment) and gave him all the attendant rights and duties towards that child.

Although the use of donated gametes was legal and becoming socially more acceptable, the donor’s identity was still kept secret and the fact that donated gametes had been used was often not disclosed. The Warnock Report recommended that gamete donor anonymity should continue, stating “anonymity protects all parties not only from legal complications but also from emotional difficulties” (Warnock 1984 p15). It was believed anonymity was needed to protect the donor legally, to encourage donors to donate and to “minimise the invasion of the third party into the family” (Warnock 1984 p25).

In 1990 the Human Fertilisation and Embryology (HFE) Act was passed, enshrining into legislation many of the Warnock Report recommendations. It introduced a system of regulation for fertility treatments and put in place systems to record information about the types of fertility treatments carried out, the patients and, crucially, about the donors themselves.

The passing of the HFE Act 1990 secured the legal status and legitimacy of the DCO, absolved the donor of all legal rights and duties towards the DCO and maintained donor anonymity (HFE Act 1990(c)). Anonymity protected the donor's identity and kept secret the fact that a donor had been used, avoiding the stigma of infertility, especially male infertility, uncertainty over social acceptance of such practices and potential damage to family relationships (Novaes 1998, Blythe and Moore 2001 cited in Blyth and Frith 2008 p75). The HFE Act gave DCO a legal right to access non-identifying donor information only once they reached 16. Whether or not to tell the DCO of their origins was left to the recipient parent(s) to decide.

Table 1: A summary of the information made legally available to the donor, DCO and donor siblings by the HFE Act 1990.

	HFE Act 1990		
	Donor	DCO	Donor siblings
Donor identifying information			
Donor physical appearance (optional)		●	●
Donor year and country of birth		●	●
Donor statement (optional)		●	●
Donor ethnicity		●	●
Donor marital status		●	●
Children (of donor, naturally conceived)		●	●

(continued on next page)

(continued from previous page)

	HFE Act 1990		
	Donor	DCO	Donor siblings
Basic DCO information (number, sex, year of birth)	●		
Donor sibling non-identifying information (via DonorSiblingLink – voluntary)		●	●
Donor sibling identifying information (via DonorSiblingLink – voluntary)		●	●

Pressure grew during the 1990s to identify donors and in 2004 the HFEA Disclosure of Donor Information Regulations (HFEA 2004) were passed. From 1st April 2005 the HFEA (2015(b)) collect the following information from donors:

1) Identifying information: name (and name at the time of donation, if different), last known address, date and place of birth,
2) The donor's physical appearance (height, weight, eye and hair colour) if provided by the donor,
3) Year and country of birth,
4) A short statement or goodwill message, if provided by the donor,
5) Ethnicity,
6) Marital status,
7) Whether they had any children, how many and their gender,
8) Their medical history.

At the age of 16, DCO can apply to access all the non-identifying information the HFEA hold about their donor, and from 18 they can apply to access identifying information.

In addition, DCO can also access non-identifying information about their donor siblings (number, sex and year of birth) from the age of 16 and identifying information from 18, provided both parties consent (HFEA 2015(b)), using the voluntary DonorSiblingLink service.

Table 2: A summary of the information made legally available to the donor, DCO, donor siblings, recipient parent(s) and naturally conceived children of the donor by the HFE Act 1990 and the Disclosure of Donor Information Regulations 2004. Note the dearth of information legally available to the donor's naturally conceived children, especially in comparison to that available to donor siblings.

	HFE Act 1990 and DDIR 2004				
	Donor	DCO	Donor siblings	Recipient parent(s)	Naturally conceived children of donor
Donor identifying information		●	●		
Donor physical appearance (optional)		●	●	●	
Donor year and country of birth		●	●	●	
Donor statement (optional)		●	●	●	
Donor ethnicity		●	●	●	
Donor marital status		●	●	●	
Children (of donor, naturally conceived)		●	●	●	
Basic DCO information (number, sex, year of birth)	●				
Donor sibling non-identifying information (via DonorSiblingLink – voluntary)		●	●		
Donor sibling identifying information (via DonorSiblingLink – voluntary)		●	●		
Basic donor sibling information (number, sex, year of birth)			●	●	

The HFE Act and the Disclosure of Donor Information Regulations (DDIR) also give the recipient parent(s) a legal right to access some non-identifying information about the donor before the DCO reaches 16. What they do with this information is left up to them but they have no legal right to access identifying donor information, even after

the DCO reaches 18. DCO cannot contact the donor's naturally conceived children and they cannot contact the DCO, despite sharing a genetic parent.

Where are we now?

One in seven couples experience some difficulty conceiving (NHS 2014) and one in ten are infertile (BMA 2004 p269), requiring the use of assisted reproduction treatments (ART) to conceive. Available fertility treatments include in vitro fertilisation (IVF), intra-cytoplasmic sperm injection (ICSI) and donor insemination (DI).

In 2013, the HFEA reported that:

- 2379 women underwent a total of 4611 cycles of DI,
- 1886 women were part of an egg-sharing agreement (where women undergoing ART donate some of their eggs to subsidise the cost of their treatment), or had treatment to produce eggs or embryos for donation,
- 2527 IVF treatment cycles started in 2013 used donor sperm.

The number of women receiving IVF and DI continues to increase, and the number of cycles using donated eggs (around 5% of IVF cycles) (HFEA 2013(a)) is also rising (see table 3).

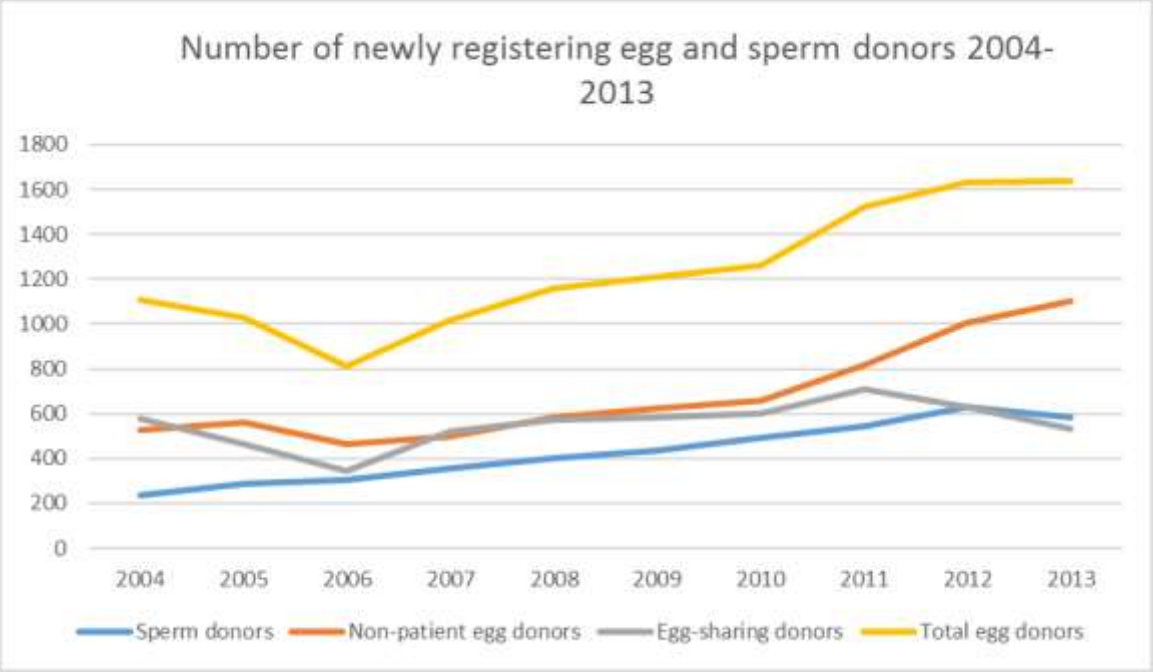
Between 1992 and 2009, a total of 35957 children were born in the UK as a result of donor conception treatments (around 2000 births a year) (HFEA 2013(c)).

Table 3: The number of ART cycles undertaken in the UK 2012-2013. (Source: HFEA 2013(a))

Treatment type	2012	2013	% change
IVF/ICSI cycles	62158	64600	+3.9%
DI cycles	4474	4611	+3.6%
IVF/ICSI cycles using donor eggs	1659	1886	+13.7%
IVF/ICSI cycles using donor sperm	2372	2527	+6.5%
Donor sperm and egg cycles (includes embryo donation)	474	693	+46.2%

Prior to the introduction of the DDIR concerns were raised that the removal of donor anonymity would be a disincentive to donate, or that it would change the demographic of those donating. There was particular concern that this would impact disproportionately on donors from certain ethnic groups, making it even harder to match donor and recipient. Despite the House of Commons Science and Technology Committee (2005 paragraph.152) identifying the effect on donor numbers as being the major contentious issue of ending anonymous donation donor numbers have remained relatively stable (see graph 1). The number of newly registered sperm donors decreased from 426 in 1993 to 256 in 1998 but since 2005 numbers have increased year-on-year and in 2010, 480 new donors were registered (HFEA 2013(c)). This has been driven by publicity and recruitment campaigns, organised by individual centres and supported by organisations such as the National Gamete Donation Trust (NGDT), which have increased the awareness and acceptability of gamete donation. The effect of the removal of anonymity on egg donors is harder to predict as many egg donors do so as part of egg sharing schemes or donate to someone known to them; but despite a decrease in 2005 numbers have been increasing steadily since 2006 (HFEA 2013(c)).

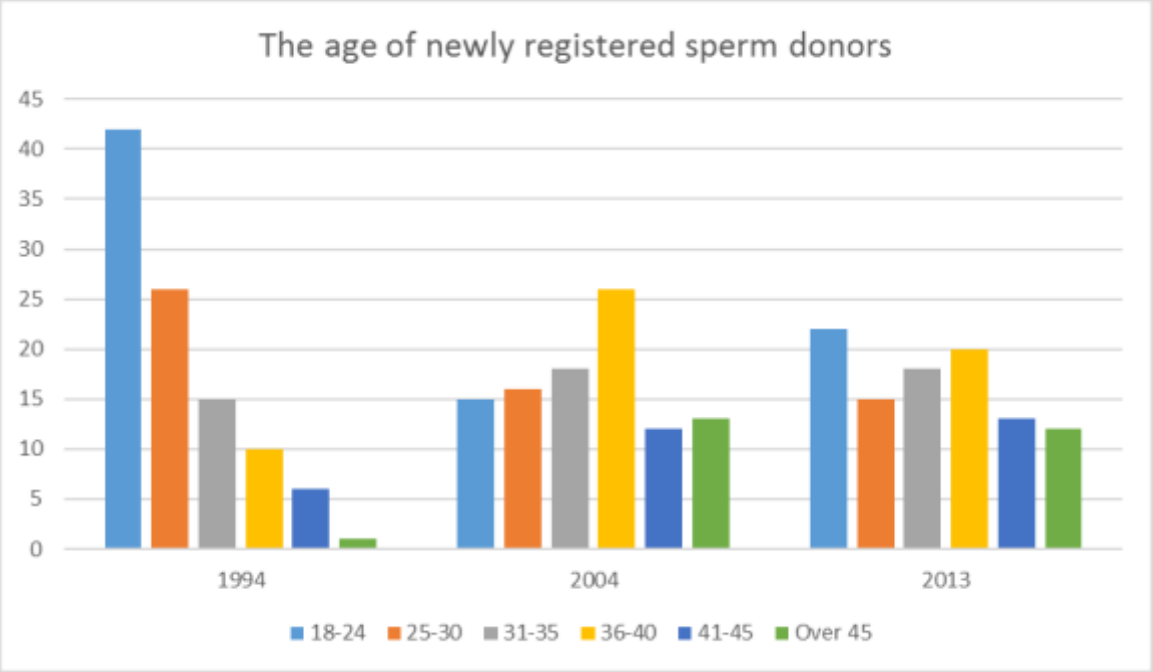
Graph 1: The number of newly registered egg and sperm donors 2004-2013. (Source: HFEA 2014(d)).



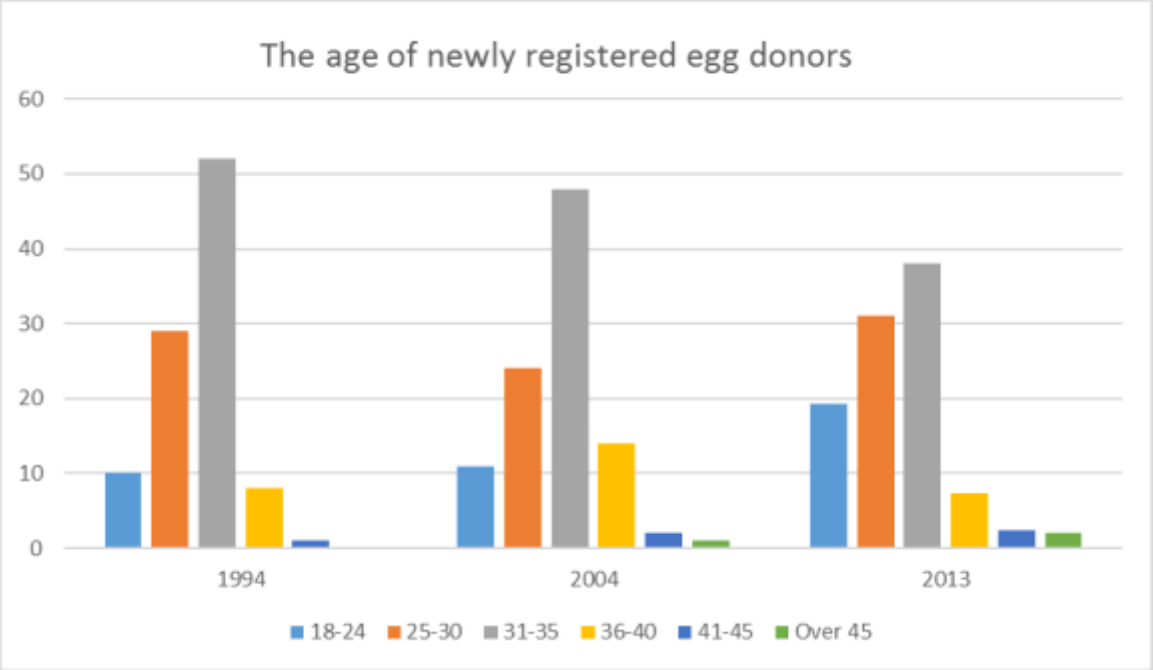
Despite the increase in new donor registrations there remains a shortage of donated gametes in the UK, leading some recipients to seek treatment abroad where waiting times may be shorter. Turkmendag et al (2008) suggest that some recipients may also seek treatment abroad to avoid UK laws on donor anonymity.

The demographics of donors, especially sperm donors, has changed considerably over the last decade and sperm donors are now more likely to be older, and with children of their own (see graph 2). The age of egg donors has remained fairly similar but they are now much less likely to have children of their own, possibly due to the increase in egg-sharing schemes (HFEA 2005) (see graph 3).

Graph 2: The age of newly registered sperm donors by percentage for 1994-5, 2004 and 2013. (Source: HFEA 2014(d) and (g))

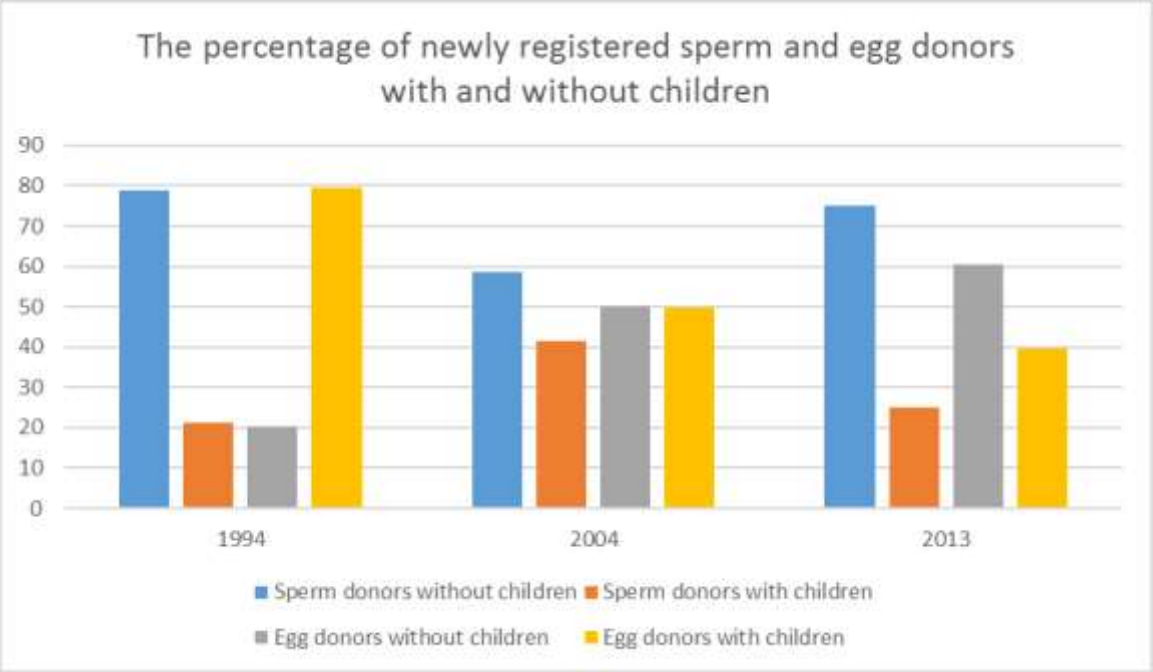


Graph 3: The age of newly registered egg donors by percentage for 1994-5, 2004 and 2013. (Source: HFEA 2014(d) and (g)).



The increase in younger egg donors and decrease in egg donors with children at the time of registration (see graph 4) is possibly due to the increase in egg-sharing schemes. The current upper age limit, set by the HFEA, for egg donors is 36 years of age, which may also be contributing to the increase in younger donors.

Graph 4: The percentage of newly registered sperm and egg donors with and without children at the time of registering 1994-5, 2004-5 and 2013. (Source: HFEA 2014(d) and (g)).



Internationally

The UK is not alone in practicing open-identity donation. In 1985, Sweden became the first country to legislate for open-identity donation, and similar legislation followed in Austria, Switzerland, the Australian state of Victoria and the Netherlands (Frith 2001 p819). In addition, countries such as New Zealand and the USA offer voluntary open-identity programs.

Worldwide, there is some variation in when access to identifying information is granted: in Austria, DCO may access the information at 14 (HLC 2015), at 16 in the Netherlands (Janssens 2006 p852) and Western Australia (RTC 2013). In Western Australia the donor's identity can be released to a DCO under 16 provided the donor and the recipient parent(s) consent. In New Zealand, the Family Court can authorise disclosure to a young person aged at least 16 as long as it is in the DCO's best interests (DIA 2015). Sweden and Victoria have a 'sufficient maturity' test, rather than a precise chronological age – more in keeping with the idea that children develop the ability to make significant decisions as they mature, rather than at a set time point (SNCME 2013, BDM 2015).

Legislation, regulation, ethics and rights

The use of donor gametes and embryos in the UK is legislated for by the Human Fertilisation and Embryology Act 2008, an amended version of the 1990 Act. The HFEA act as the regulatory body who ensure that legislation is adhered to, ethical standards of treatment and care are maintained and that the rights of all those involved in the process of gamete donation, be they donors, recipients or the DCO, are upheld.

The rights of those involved in gamete donation are complex, interlinked and often competing but is important to understand them to be able to fully examine whether or not the rights of the DCO should be the ruling bioethical principle of the disclosure of information regarding gamete donation in the UK.

Chapter Two: Rights

To understand why the DDIR is such an important and controversial piece of legislation it is necessary to understand not only the interests and rights on which it is based, but also the interplay of these interests and rights. Legislation involving gamete donation impacts on many different parties, each with competing, and potentially conflicting, rights of their own. It is important to understand not only what rights are per se but also to understand what the specific rights, of all the interested parties, are with respect to the DDIR.

What are rights?

Rights are justified claims to the protection of a person's important interests (Gewirth 1995 p776), and this is a protection which is owed to persons for their own sake.

Rights mean different things in different situations and may be categorised in different ways. There are moral and legal rights and positive and negative rights. The 1948 United Nations Declaration of Human Rights contains security, due process, liberty, political, equality and social rights. The right-to-know does not fit neatly into one particular category, but instead encompasses due process, liberty and equality rights.

Hohfield (cited in Gewirth 1995 p776) proposed four different meanings to 'a right': claims, liberties, powers and immunities. He considered claim-rights to be the most

important because they require a duty from others to not to interfere with a person having the object of their right, or a duty to actually assist them in having the object. In the case of the DDIR, DCO have a claim-right to know their donor's identity and others (recipients, HFEA, etc.) have a duty not only to not prevent them from accessing this information but also to assist them in doing so.

The right-to-know may also be described as a positive right, in that DCO can only exercise this right with the assistance of others. This is because DCO cannot begin the process of applying for identifying information unless they have been told of their origins. Similarly, the right-to-know can be said to involve "perfect duties", which impose specific duties on identifiable people in relation to "the notion of justice, autonomy and perhaps also non-maleficence" (Almond 1994 p512).

Rights carry more weight than an interest does, as having a right means that there is a strong justification for having one's interest protected. MacCormick (1982 p154) explains having a right justified by the interests theory as "'having one's interests protected in certain ways by the imposition of (legal or moral) normative constraints on the acts and activities of other people with respect to the objects of one's interests'". The DCO's interest in knowing their origins can be justified on two main grounds – an interest in knowing their familial medical history and a "psychological need for identity" (O'Donovan 1988 p29), and this justification under the interest theory gives weight to their right-to-know.

The right-to-know means that DCO are personally entitled to information for their own sakes. Interestingly, if a utilitarian approach is taken to the justification of this claim-right the outcome may be different. The DCO still has an interest in knowing their

donor's identity but, after taking into account the impact of this knowledge and the interests of the donor, recipient(s) and other parties, this interest may not translate into a right.

The DDIR re-enforces the DCO claim-right-to-know by making it a legal right. The right-to-know is a justified legal right because the object of the right, the identifying information, is considered necessary for the freedom and well-being of the DCO.

Rights are rarely stand-alone entities. In reality, rights are inextricably bound with duties, responsibilities and interests, especially in situations where the exercising of one person's rights may violate the rights of another. In the case of gamete donation it is possible to identify the rights of all the parties involved but deciding whose rights take precedence is a balancing act, and there will always come a point where an individual's rights should be infringed (Dancy 1993 p227). The difficulty comes in deciding how and why an individual's rights should be infringed without denying equal moral status to another of the parties (Warren 1993 p303). Consideration must be given to the degree and importance of the good expected as a result of that right being exercised, whilst remembering that the "universality of human rights requires that each person act with due regard for other persons' freedom and well-being as well as her own" (Gewirth 1995 p776).

The DDIR is not the only piece of UK legislation that grants a legal right to information held by medical bodies. The Access to Medical Reports Act 1988 (1988 Chapter 28) allows individuals to access medical information about themselves held by medical practitioners. However, although this is a legal right, this can be denied if it is believed that it will cause serious harm to the physical or mental health of the patient or

someone else. The right to know information about ourselves is therefore clearly not an inalienable one.

Where do they come from?

The legal right-to-know evolved from an increasingly strong belief that we should be able to know our genetic identities. With advances in reproductive technology, genetic testing and changes in public attitudes towards the use of ART, and the resulting families, these moral beliefs gained sufficient strength to become legal rights.

The rights of the DCO: the right-to-know

A number of arguments have been put forward in support of the right-to-know one's genetic origins. The two most common are that it is "essential to human wellbeing" and that "people have the right to the truth about their origins" (Frith 2001 p821). They are based on the idea that by not knowing our genetic origins we are being harmed and that we have a right to the truth about ourselves.

The argument to tell to prevent harm

Knowing their donor's identity is believed to be in the DCO's best interests because psychological wellbeing is "intimately connected to a sense of identity and heritage" (Brazier 2011 p371). Maclean and Maclean (1996 cited in Turkmendag et al 2008)

argue that because disclosure of donor identity is in the DCO's best interests, this must therefore override any desire for secrecy on the part of the recipient(s).

Although it has been claimed that not knowing their genetic origins is harmful to DCO (Snowden and Mitchell 1981, Turner 1992, McWhinnie 1996 cited in Frith 2001 p821) there is little definitive research assessing the psychological impact of not knowing one's genetic parents, either in adoptees or DCO. There is evidence that DCO, like adoptees, are often curious about their genetic parents and desire more information about their physical appearance and characteristics, but this in itself is not indicative that not knowing is harmful (Humphrey and Humphrey 1986 cited in Frith 2001 p821). Nevertheless, the DCO's need for a connection to the donor, genetic or otherwise, should not be disregarded. Cohen (cited in Vanfraussen et al 2001 p2020) argues this connection is important for our sense of self because "hereditary links are used to establish one's self-image and identity". There is little evidence to support this and the argument is further undermined because, by 18 when DCO may seek identifying information, our personalities are already mostly formed. This is supported by Ruyter (1997 cited in Turkmendag et al 2008), who claims that while knowledge of genetic parents can contribute to the child's inner development it is not essential.

Although DCO have described feelings of incompleteness as a result of not knowing their genetic origins there is little evidence to show that receiving identifying information gives them the sense of completeness they lack (Turner and Coyle 2000 pp.2047-2050, McWhinnie 2001 p812). The need-to-know for psychological well-being has been countered by Herring; "To encourage people to think that genetic links are important is to encourage an outdated idea of parenthood. Feelings of being

incomplete without knowledge of one's genetic identity are social constructions and need to be challenged, not pampered" (Herring 2012 p383).

Whilst many studies have looked at adoption, donor conception is harder to examine and is also not directly comparable to adoption (Shenfield 1994 p1350). DCO are usually genetically related to one recipient parent and do not encounter the same abandonment issues. Studies examining the potential harm done to DCO by not knowing their origins are further complicated by the fact that, despite the passing of the DDIR, few recipient parents tell their DCO of their origins.

The right to the truth

Irrespective of the issue of harm, it is argued that DCO have a right to be told the truth about their genetic origins, even if it is believed that the truth will not benefit them in any way. Warnock said "I cannot argue that children who are told of their origins, if they are AID children are necessarily happier, [sic] or better off in any way that can be estimated. But I do believe that if they are not told they are being wrongly treated" (Warnock 1987 p151).

The BMA (2004 pp.288-9) comments that many naturally conceived children are not the children of those they believe to be their parents. Estimates vary but recent a systematic review puts this figure between 0.8 and 30%, with a median value of 3.7% (Bellis et al 2005 p749). As paternity tests are not widely available, and there is no obligation in the UK for mothers to name the child's father on the birth certificate, "it cannot be argued that as a principle there is a general entitlement to know ones

parents" (BMA 2004 p289). With natural conceptions, the mother's interests in keeping the father's identity secret take precedence over the child's interests in knowing his identity (Bellis et al 2005 p753). Nevertheless, knowing the donor's identity can be important, and sharing this information, especially within the family, is important for openness and transparency.

This is supported by O'Donovan (1988 p38), who argued that not telling the DCO of their origins cannot be justified as being in the child's best interest: "The argument that the deceived would be better off not knowing, or would prefer not to know, runs into problems of lack of consent. There can be no consent in advance of lies about parenthood, for this would defeat the object. So the justification is advanced that the liar knows better than the victim what is good for the victim. This type of paternalistic argument, generally put forward in relation to persons of lesser capacity, is dangerous here. The child will develop into an adult."

Openness and honesty are clearly preferable. Secrecy and deception, as well as causing stress and anxiety within the family, undermine trust which is vital for stable and strong relationships. Studies have found that DCO discovering their origins has created feelings of mistrust within the family, of loss created by a lack of knowledge about their genetic identity, and frustration at not being able to discover more (Turner and Coyle 2000 p2041). McWhinnie (2001 p812) reports feelings of anguish, resentment, anger and a loss of a sense of identity and self, which are often more acute if the discovery has been accidental, rather than planned. It is not clear whether it is discovering that they are donor-conceived that causes these feelings, or whether it is the nature and timing of the discovery. Some DCO who have discovered their origins

reported feeling more concern over the impact that the prolonged secrecy and deception surrounding their conception has had on parental and family relationships, than about the fact that they were donor conceived. They have described the effect of the secrecy as “caustic”, “corrosive” and “detrimental” (Blyth 2012(b)). A lack of openness about their origins may also suggest to the DCO that their recipient parent(s) are ashamed of their origins, or even of them (HFEA 2012(d)).

Preliminary studies reported by Snowdon and Snowdon (1983 cited in Gillon 1994 p613) showed children do not react adversely to being told of their origins, provided the information is given in a purposeful and planned way. This is supported by Blyth’s assertion (2012(b)) that early disclosure avoids the need for deception and secrecy, and the effect they have on family relationships, and provides “an opportunity for offspring to affirm their parent’s choice of donor conception as a means of family building” (Blyth 2012(b)).

When considering the importance of knowing ones genetic identity and origins, Lusk (1988 cited in Gillon 1994 p613) suggests it is more useful to think in terms of the resulting ‘adult’ than the resulting ‘child’. But it is still not clear whether what is best for the resulting ‘adult’ is more about preventing secrecy and deception within the family than a need to have identifying information.

The legal basis of the right-to-know

Article 7 of the United Nations Convention on the Rights of the Child 1989 (UNCRC 1989) states the child has “as far as possible, the right to know and be cared for by his

or her parents." In the context of gamete donation and DCO, 'parent' has been taken to mean the donor. However, the Convention does not define 'parent'. A parent may be a genetic parent but in this day and age there is more to parenting and family structures than just genetics. In addition to genetic parents, the Education Act (1996 Section 576) defines a parent as any person who, although not a genetic parent, has parental responsibility for a child or young person, or any person who has care of a child or young person. Thus it is not clear that Article 7 alone grants a right-to-know for the DCO. Additionally, the donor has no legal rights or responsibilities towards the DCO, and the DCO can make no legal claim on the donor. Yet invoking Article 7 in support of the DDIR may also invoke the right of the child to "be cared for by his or her parents" (UNCRC 1989), placing it in conflict with existing UK donor legislation.

The Human Rights Act 1998 (HRA 1989(a)), which incorporates the European Convention on Human Rights, has also been cited in support of the DCO's right-to-know. Article 8, the right to respect for privacy and family life, is said to be contravened by any law prohibiting DCO from identifying their donors. In *R (on the application of Rose and another) v Secretary of State for Health and another* [2002] 3 FCR 731 Scott Baker J concluded that "respect for private and family life requires that everyone should be able to establish details of their identity as individual human beings. This includes their origins and the opportunity to understand them. It also embraces their physical and social identity and psychological integrity". Being able to know one's genetic identity is clearly important but identity is more than mere genetics; nurture may play just as important a role in shaping and developing physical and social identity and psychological integrity as nature.

Article 8 protects the right to respect for private and family life, prohibiting interference by a public authority except under certain conditions. One such condition is "for the protection of the rights and freedoms of others" (HRA 1989(b)) - "others" could conceivably mean the donor or recipient parent(s). The Human Rights Act does not define what is meant by family, and today's families include more than purely genetic relations. In *Re R* ([2002]), Scott Baker J observed that "private and family life is a flexible and elastic concept incapable of precise definition". It is also clear that the Human Rights Act recognises there may be conflict between the rights of family members – respecting privacy for one may mean violating it for another.

Similarly it has been argued that maintaining donor anonymity contravenes Article 14, the prohibition of discrimination; maintaining donor anonymity means DCO are the only group of people legally prevented from discovering their genetic origins.

Although these arguments are compelling it should be remembered that these conventions were not written with gamete donation in mind (Frith 2001 p821). Article 7 of the Convention on the Rights of the Child 1989 was originally developed following concern about stateless children and Article 8 of the Human Rights Act was a response to the abduction of babies at birth by the Argentinian military regime (Fortin 2009 p345). They should therefore be applied to the debates regarding anonymous vs open-identity donation and the right-to-know with some caution.

In 2002 UK donor anonymity was challenged as a breach of Articles 8 and 14 of the Human Rights Act. In *Re R* ([2002]) the claimants were seeking access to non-identifying donor information. The court held that Article 8 was engaged: "respect for

private and family life incorporated the concept of personal identity and everyone should be able to establish details of his/her identity as a human being. This included the right to obtain certain information about a biological parent who would inevitably have contributed to the identity of his/her child." Scott Baker J went on to conclude that the distinction between identifying and non-identifying information was not relevant to whether or not Article 8 is engaged but that the distinction is relevant to the "balancing exercise of the other considerations in art 8(2)" (*Re R* [2002]). It is the balance between article 8(1) and (2) that is crucial when discussing the DCO's right-to-know and the rights of the other interested parties.

McWhinnie (1988 cited in Gillon 1994 p613) argues that donor anonymity, in addition to preventing DCO from knowing their genetic identity, also denies them chance to access their identity as it appears in official registers. Whilst undoubtedly true, the situation is little improved post-DDIR introduction. There is currently no UK legislation that ensures DCO are told of their origins, and open donation alone does not appear to be sufficient to ensure that DCO are able to access their genetic identities. Although the DDIR places a positive obligation on the state to assist DCO in identifying their donors it falls "short of providing an unequivocal right to a donor-conceived person to learn the identity of his or her donor." (Blyth 2012(a) p311).

How to ensure DCO are told of their origins, and can therefore exercise their right-to-know, has often been debated and, as yet, no satisfactory solution has been found. In August 2007, the Joint Committee on the (Draft) Human Tissue and Embryo Bill debated whether a legal right to be told was needed. Arguments in favour included

that as the state was involved in assisted conception, it should not be actively involved in deception, although it may be argued that any deception is practiced by the recipient parents rather than the state. Many witnesses believed openness, honesty and early disclosure should be encouraged but not legislated for, and some argued legislation would infringe recipient parents' reproductive and parental autonomy and responsibility (Joint Committee 2007 paragraph.269-271). The Government rejected the Joint Committee's recommendation to put 'By donor' on the DCO's birth certificate but agreed to keep the matter under review (Joint Committee on Human Rights 2008 pp.57-58).

A further balance must be found between the right-to-know of as yet unborn DCO and the potential effect of the DDIR on donor numbers. Although statistics now suggest that the DDIR has not adversely affected donor numbers there is still a shortage of donors, and it is not known if more donors would be available if a parallel anonymous system was also available. If this is the case, Campbell (2006) argues that the "net effect of the policy is that children who would otherwise have come into existence do not now do so because donors cannot be found". These children cannot exercise their right-to-know because the very presence of their right may cause them, directly or indirectly, not to be born.

Whilst it is often argued that children have a right not to be deceived about their genetic origins, the fact that the truth can be damaging or traumatic is often overlooked. Open-identity donation is potential harmful to DCO, as well as to the donor, recipient(s) and wider family, and their interests and rights should not be overlooked.

The rights of the donor

It could be argued that donors have a right under Article 8 of the Human Rights Act to maintain their anonymity to protect their private and family life. However, given that gamete donation is a voluntary act and donors consent to the holding and releasing of identifying information by the HFEA this argument is weak. It would perhaps have more weight if it was proposed that the DDIR had been applied retrospectively (a challenge that could be mounted under the Human Rights Act 1990), or if it were suggested that donors be obliged to reciprocate contact with DCO.

There is a marked disparity in the amount and type of information that DCO can access and the amount that the donor can. An argument can be made that it is important for the donor's psychological well-being to discover the identity of, and have the chance of contact with, the DCO. Donors often report thinking about the offspring born as a result of their donation, and of a desire to know more about them (Jadva et al 2011 pp.641-642).

The legal rights of the donor, provided they have donated through a HFEA licenced clinic, are clear. Sperm donors are not the legal parent of the DCO, have no legal obligation towards them, are not named on the birth certificate, have no parental rights and cannot be asked to support the DCO financially. The situation is even more straightforward for egg donors: the birth mother is considered the legal mother of the DCO, even if she has conceived using a donated egg. The DCO's legal father, or second parent, is the birth mother's husband, provided he has consented to treatment, or the

birth mother's partner, provided they are named on the 'Consent to Parenthood' forms. The legal rights of the genetic parents of donated embryos are less straightforward, and the legal parents of the embryo are determined by the HFE ACT 1990. The use of donated sperm by single women is also a grey area. The birth mother is the legal mother but the donor could be considered the legal father (HFEA 2012(b)).

The rights of the recipient(s)

Very few, if any, recipients will use donated gametes with the intention of the donor becoming a 'parent' to their child. They are far more likely to view the donated gametes as having been donated to allow them to become parents and have a family of their own; as a means to an end, with the donor as the facilitator of the process.

The possibility that DCO could discover the truth about their origins may be unsettling for many recipient parents; they may even perceive contact, and a possible relationship, with the donor as a threat to themselves and their family. The donor may be happy with their role as donor and not wish for involvement as a parent but this is not always the case. Open-identity donation creates the potential for damage to family relationships, especially the relationship between the recipient father and DCO (Roberts 2000 cited in Herring 2012 p382).

It has been argued the recipient parent(s) also have a right to privacy and respect for their family life and as such should not be compelled to tell the DCO of their origins if they choose not to (Walker 1999 cited in Frith 2001 p822). Although accessing donor information may be positive for the DCO, maintaining family privacy and protecting

the family “from interference by a third party” (Vanfraussen et al 2001 p2023) may also be beneficial for the DCO. The recipient parent(s) are autonomous, making their own reproductive decisions and exercising their parental rights in how they choose to raise the DCO. In choosing not to tell, there is a conflict between the DCO’s right-to-know and the interests/rights of the recipient parent(s). This is further complicated by the fact that they may choose not to tell because they do not consider that doing so is in the best interests of the child. Although children are acknowledged and accepted as rights-holders, they are able to exercise relatively few rights independently and are dependent on the decisions of parents/guardians for the protection and upholding of many more.

In 2006, Professor Sir Colin Campbell, founding chair of the HFEA (1990-1994) called for the restoration of sperm donor anonymity, in effect reversing the DDIR. Irrespective of the effect on donor numbers, he argued that the DDIR gave the “putative interests” of a person not yet conceived greater weight than the “legitimate interests” of the would-be parents (Campbell 2006).

The rights of others

The families of DCO do not consist simply of the DCO, recipient parent(s) and the donor. There are wider family members who may be affected by both the donation and by subsequent potential contact between DCO and donor, and their interests and rights are important too.

Although recipient (i.e. non-donor) grandparents have no direct legal right to contact with their grandchildren, they can apply to court to make an application to see them under a Court Order (Davies 2010). Contact with grandparents is often held to be beneficial children (see *Re W (A minor) (Contact: Application by Grandparent)* [1997] 2 FCR 643) and *Re C (art 8 order: grandparents' application for leave)* [2003] NIFam 13 Family Division). As yet, donor grandparents and other donor family members have no legal right to contact with the DCO, and as DCO-donor contact can only occur once the DCO reaches 18 this is unlikely to change soon.

The interests of other family members may also extend into the future. There may be a time when donors, for example, seek a legal recourse to have contact with the children of their DCO, their genetic grandchildren. Conversely, Blyth (2012(a) p313) postulates that the "…..descendants of a donor-conceived person may have an interest in knowing the identity of their parent's donor, an interest that may not be realised if their parent has not sought this information for him or her self – possibly because they were not interested in accessing this information for themselves or were unaware of their status and/or the existence of this information." Similar cases involving the descendants of adopted children have already occurred. In *Re X (Adopted Child: Access to Court File)* [2014] EWFC 33, the daughter of the adopted person successfully applied to the court for information about her genetic grandmother. What weight, if any, should be given to their interests and rights? Would the right-to-know pass down to the DCO's genetic descendants? If knowing one's genetic origins is so important, descendants of DCO could presumably also mount a legal challenge under Articles 8 and 14 of the Human Rights Act.

A comparison with adoption

Since 1976 adopted children, from the age of 18, have had the legal right to access their original birth certificate (Adoption Act 1976 Section 51). The Adoption and Children Act (2002 Section 60) gives an adopted child the right to access any available information about themselves, unless the High Court orders otherwise.

The importance for adopted people of having information about themselves and their background has long been recognised. In 2001, Scott Baker J found that "many adopted people wish to have information about their history and background including the reasons for their adoption. Many find it important to have a complete personal history in order to develop a positive sense of identity" (*Re Gunn-Russo v Nugent Care Society and another* [2001] EWHC Admin 556). Now, those involved in adoption are encouraged to participate in life story work. This is a method of recording significant information and events for adopted children to help them know and understand their past (Be My Parent 2012(a)). It includes descriptions of their birth families, information on their place of birth, significant people in their lives and their care history to help adopted children understand their origins and develop a sense of identity (Be My Parent 2012(a)). Additionally, there may be direct or indirect contact between the birth family and adopted child. Whilst this does not happen in all cases, it is recognised that some form of contact may be beneficial to the child. This is undertaken on a voluntary basis and although it may be recommended by social workers or the court there is no legal obligation by the adoptive parent(s) to agree (Be My Parent 2012(b)).

There are clearly differences between adoption and donor conception. Life story work is not used for DCO, possibly because the nature of the conception, pregnancy and birth make it easier to conceal the child's origins. The DCO is usually genetically related to one recipient parent and, as they are born into the recipient family, all their significant events and people are known to the recipient family, and to them. The only exception to this, should the recipient parent(s) choose not to disclose, is information about their conception and about their donor. Available information about the donor may be limited, especially if the donor has only completed a basic profile.

There are also significant differences between donors and birth parents. A donor is defined as a giver or contributor (The Free Dictionary); a person donating gametes facilitates others to become parents and have a family. Birth parents are not donors.

They do not have children with the intention of relinquishing them to allow others to be parents. A donor may view their involvement as complete once the donation has been made, neither requiring nor expecting any further involvement, whereas birth parents may always view themselves as parents.

Where the two scenarios are similar is in that although both DCO and adopted children have a legal right to access information about their genetic identities once they reach 18, there is no legal requirement for them to be told about their origins. As with donor-conception, there is strong guidance from the British Association for Adoption and Fostering that children should be raised knowing that they are adopted, and that this information should be given from a young age and in an appropriate manner (BAAF 2014). Disclosure may be difficult in both adoption and donor-

conception but it is important because without it, neither group can exercise their right-to-know.

Although experience from adoption regarding how and when to disclose information may be helpful it is not often used. Turkmendag et al (2008) emphasize that "adoption is a *substitute* for procreation whereas donor conception is a *form* of procreation: the act has its own integrity and completeness – it is the would-be parent(s)' act and the child is unquestionably their child". With donor conception, one recipient parent is usually genetically related to the DCO, there is a visible pregnancy and no obvious infertility, and "the donation [is] of gametes rather than giving up one's child" (Scheib et al 2003 p1125). This is especially true for heterosexual couples, where the presence of a father means conception origins are less likely to be questioned.

Despite the differences between adoption and donor-conception, much of the evidence on the harm caused by secrecy (Shenfield and Steel 1997 p392) and the importance for a child to know his/her origins (Almack 2006 p7) is drawn from the literature on adoption.

There are also differences between DCO and adopted children in terms of the medical history of their donor/birth parent that they can access. Donors must inform the HFEA of any medical conditions, or family history of such conditions, prior to donation (HFEA 2012(b)) whereas adopted children rely on the Adoption Registration Service GP to GP service (HSCIC), which passes relevant hereditary information between the GP's of the birth parent and adopted child, provided the birth parent can be traced. Thus adopted children, and their adopted parents, have far less information than the DCO.

It is worth noting that while Article 8 of the Human Rights Act can be invoked in support of the right-to-know for both DCO and adopted children, on the basis that knowing their genetic origins is important for their sense of identity and psychological wellbeing, there is no corresponding right for either the gamete donors or birth parent(s). It is difficult to argue that knowing their biological child is important for their own genetic identity but the argument that they have a similar right-to-know for their sense of self and wellbeing is much stronger. In fact, Article 14 is often invoked in support of the right-to-know for DCO and adopted children because it would be discriminatory to deny them a legal right to know their genetic origins and family, under Article 8. But is it not similarly discriminatory to prevent donors and birth parents from having any legal right to identify and contact their children? Currently, birth parents wishing to contact their genetic children must join the Adoption Contact Register. This is a voluntary contact register administered by the Registrar General, which facilitates contact between the adopted child and birth parents, once the adopted child reaches 18 and only if they wish to contact their birth relatives (Adoption Act 1976). Donors wishing to contact their DCO may register with the HFEA or organisations such as the Donor Conceived Register, but again contact is voluntary and can only occur once the DCO reaches 18.

Translating rights into reality

Despite clear and unambiguous legislation as detailed by the DDIR it is evident that in practice the situation is more complicated. The same arguments that are often cited in

support of the DCO's right-to-know can also be cited in support of opposing rights of the donor or recipient parent(s). In order to understand how and why and whether these rights are translated into reality it is necessary to look in more detail at the DCO, donor, recipient parent(s) and their respective families.

Chapter Three: The Donor-Conceived-Offspring

The concept of family

Using donor gametes to conceive a child challenges previously held ideas of family and personal identity (BMA 2004 p269). Genetically, the child is only related to one (or possibly none) of the recipient parent(s), yet socially, emotionally and legally the recipient parent(s) are considered the parents. The child is born to them, and raised and nurtured by them. Although a genetic parent, the donor has no legal responsibility towards the child and, in the vast majority of cases, no emotional or social contact or responsibility either (see Appendix 1 for a hypothetical case study illustrating the complex links between DCO, recipient parent(s), donor and their respective families).

There are numerous reasons why gamete donors choose to donate and a wide variety in how donors view their DCO. Whilst some donors consider themselves to be parents to their DCO many do not: "'…this was me providing a service to other people who would be parents'…. 'I'm not a parent. I would never consider that I was any sort of parent, but certainly I've got a role in their life just letting them know what their genetic heritage is'" (Kirkman et al 2014 p735).

For DCO, learning of their origins may threaten their existing identity (Turner and Coyle 2000 p2042) and this may be felt more acutely with the accompanying knowledge that they can identify their donor.

The welfare of the child

Both the HFE Act 1990 (1990(a)) and the HFEA Code of Practice (2014(c)) contain requirements to consider the welfare of the child, where 'the child' is taken to mean the child born as a result of the donation or procedure.

The 'need for a father'

Under the HFE Act 1990 (1990(a)), clinics must consider the "welfare of any child who may be born as a result of the treatment (including the need of that child for a father) and of any other child who may be affected by the birth". In 2008, the 'need for a father' was replaced by "the need of that child for supportive parenting", to reflect the changing nature of the family (HFE Act 2008) whilst maintaining the emphasis on a supportive family environment.

Informing DCO of their origins

Until 2003, the HFEA Code of Practice (2003 p31) made specific reference to the need to consider, within the assessment of the welfare of the child,

"(i) A child's potential need to know about their origins and whether or not the prospective parents are prepared for the questions which may arise while the child is growing up

(ii) Family attitudes towards such a child

(iii) Implications which may arise if the donor is known within the child's family or social circle."

The introduction of the DDIR, which recognised in law the right of the DCO to know their genetic identity, necessitated a change in the Code of Practice. These considerations are no longer listed but the most recent Code (HFEA 2014(c)) does detail when and how non-identifying and identifying information may be obtained, as well as recommendations that DCO are told of their origins early in childhood. It also stipulates that those seeking treatment with donated gametes should be made aware before treatment that questions surrounding their child's origins may arise and that they should be encouraged to be open with their children from an early age (HFEA 2014(c) p168).

The Code no longer includes specific reference to the need to consider the attitude of the family, or the implications of the donor being known to the family. This raises a number of interesting issues that the HFEA have not been able or willing to clarify. It is possibly because it is hoped that the increasingly accepting societal attitude towards gamete donation is leading to recipient parents becoming more open about their use of donated gametes with family and friends.

'Any other child'

The phrase 'any other child' is frequently used throughout the HFE Act 1990 and the Code of Practice. It is not defined but is commonly taken to mean 'any other child of the recipient's family'.

Prior to the introduction of the DDIR, these were the only other children likely to be affected by the use of donor gametes, but following the introduction of the DDIR the donor's naturally born children may also be affected. They may find themselves faced with half-siblings they were previously unaware of, and the effect on their welfare (especially if they are still children when the DCO makes contact) may be considerable.

It is therefore not unreasonable to challenge the Code of Practice's assertion that welfare of the child assessments do not need to be carried out on gamete donors (HFEA 2014(c) p77) or to suggest that greater information and support should be given to potential donors about the effect on their existing or future children. Now that the DDIR has created a conduit for DCO-donor contact "any other child who may be affected by the birth" (HFE Act 1990(a), HFEA 2014(c) p77) must surely include the donor's own children.

Open-identity donation

Given the detailed health information potential donors must provide to the HFEA, accessing knowledge of one's genetic background for health reasons fails as an argument for open-identity donation. The main benefit of open-identity donation appears to be to allow the DCO to have increased knowledge about their genetic background and identity.

Many DCO studies have revealed that common reactions to discovering their origins include curiosity, interest and a desire to know more about the donor's physical characteristics, personality traits and interests (Rumball and Adair 1999 p1396,

Vanfraussen et al 2001 pp.2021-2022; Snowdon 1990, Lindblad et al 2000 cited in Lycett et al 2005 p811). Open-identity donation gives recipient parents more information to give to the DCO, avoiding the sense of "futility" for parents and DCO that may result from having incomplete knowledge about the child's origins (Cook at al 1995(a) p553, Daniels et al 1995 p1214, Vanfraussen et al 2001 p2021; Snowdon et al 1983, Baran and Panor 1993, Brewaeys 1996, Lindblad et al 2000 cited in Scheib 2003 p1116).

Studies examining how children respond to learning of their DI origins have reported the experience as neutral to positive for the children and recipient parents concerned (Rumball and Adair 1999 p1396, Vanfraussen et al 2001 p2022, Lindblad et al 2000 cited in Scheib et al 2003 p1117). Scheib et al (2005 p243) reported that disclosure of their origins had a neutral to positive effect on relationships between the DCO and recipient parent(s). DCO felt comfortable having a donor and many reported that it did not affect their lives or their security within their families, although there was considerable variation in their openness to discussing having a donor.

The same study found that DCO felt somewhat positive about their donors and that for 86% their "overwhelming feeling was curiosity about the donor", with over 50% feeling appreciative towards their donor. Over 82% of DCO wanted contact to get more information about their donor (Scheib et al 2005 pp.244-247) with only 50% wanting contact to form a relationship. Of those, 50% wanted a friendly relationship and only 11% wanted a parent-child relationship. This curiosity about the donor supports Hewitt's (2002 p19) findings that DCO are "interested in knowing their donor as a person, a fellow human being", and Vanfraussen et al's finding that contact with

the donor allows the DCO to learn more about themselves and increase their sense of identity (Vanfraussen et al 2003 – cited in Scheib et al 2005 p248).

Around 30% felt anxious about meeting their donor, with a similar number feeling excited, and significantly only 10% felt the donor was an important person in their life (Scheib et al 2005 p244). This is possibly because "social links are established between the procreator and the child, not with the donor" (Turkmendag et al 2008). This is supported by Scheib et al's findings (2005 p245) that 76% of DCO described their ideal donor using positive character or physical traits, and only 44% described the donor by the positive interactions they would have with the DCO. Scheib concluded that DCO were "mostly hoping for a donor who was simply a good, open-minded person, who would be open to contact and not necessarily be heavily involved in their life" (Scheib et al 2005 p245). Similarly, Siegels et al (2008 p239) found that the DCO's relationship with their recipient parent(s) was far important to them than the method of their conception.

Scheib et al (2005 p247) also examined DCO plans for donor identity-release, and found that 86% of DCO were at least moderately likely to request their donor's identity, but there was considerable variation in when they felt they would do this, with only 55% who thought they would do so at the age of 18. Although requesting identifying information does not necessarily lead to contact, 82% thought that they would be moderately likely to attempt contact (55% at the age of 18). Of the DCO questioned for the study the majority hoped they would be able to make initial contact indirectly via the sperm bank (60%) or by letter or email, perhaps to help protect themselves from a negative outcome of attempting contact.

Nearly 80% of DCO were interested in the donors' feelings about being contacted, perhaps demonstrating an understanding of the impact contact can have on donors too. They reported being concerned about respecting the donors' privacy and not wanting to intrude on their private lives.

Can the truth be harmful?

It is assumed that DCO need to know their donors identity, and possibly to form a relationship of some kind, because this is believed to be best for the DCO. But what if the relationship is not a positive one? The donor may reject attempts at contact or contact may be difficult, creating an awkward and strained relationship. Can this sort of relationship be said to be in anyone's best interests, let alone the DCO's? A study by Carsten (2000) of adoptees searching for their genetic parents found the meetings did not always result in an instant bond or deep recognition and many became insignificant, showing that whilst the desire to know is strong the desire to start or maintain a relationship is less so.

Many recipient parents have expressed concern and anxiety over whether the donor would meet the DCO's expectations or, in families with more than one DCO, they have expressed concern over the effect on the other children, who may not have donors willing to reciprocate contact (Scheib et al 2003 p1119-1120).

Little has been said about the possibility that being contacted by their DCO may be harmful for the donors, but given that the majority of donors cited wanting to help others a main reason to donate and that only 14% viewed their relationship with the

DCO as a parental one (Jadva et al 2011 pp.641-2) it is reasonable to assume that being identified and contacted by their DCO will create some conflicting emotions for donors too.

Chapter Four: The Donor

The role of the donor is vital – without them, recipients would be unable to fulfil their desire to become parents. The donor helps to create a child and a family about which they will be given little information and no responsibility. This can be difficult for donors, especially as there is a strong social sense of responsibility towards one's offspring in many societies (Daniels 1986 cited in Gillon 1994 p611). Donors have reported feeling concern about their DCO and the life they will have (Jadva et al 2011 p641, Gallagher 2014). Although donors have no legal responsibilities towards the DCO they may feel they have a moral responsibility for them (Jadva et al 2011 p644).

Donors also differ in how they perceive their relationship to the DCO. Many don't view themselves as parents, instead believing that "the parent is the person who brings them [the DCO] up" (Gallagher 2014). Some view their relationship as that of a good friend or family member but others consider they have a parental role, regarding the DCO as their own child (Jadva et al 2011 p642). This is countered by Wallbank (2004 p260), who argues that "to contribute one's genes to the creation of a child is not congruent with the social role of parenthood".

Although the average age of donors has increased, the majority do not yet have children of their own (HFEA(d) – net.2015) and may not feel that they are ready to become parents – "at my age now I don't know I would be a good parent" (Gallagher 2014).

Why do donors donate?

There are many reasons why people choose to donate their gametes: a desire to act altruistically to help others to become parents (either those known to the donor or strangers), a wish to ensure their own DNA is carried on or to confirm their fertility, financial motivation (payment for donation or donating in return for subsidised fertility treatment) (Jadva et al 2011 p641).

In the UK, the HFEA prohibits payment for donation, but does allow the payment of compensation. Sperm donors receive £35 per clinic visit and egg donors receive £750 per cycle, and both have the provision to claim an excess to cover higher expenses (travel, accommodation, childcare) (HFEA 2012(c), 2014(a) – net.2015).

Egg donors and egg-sharing

A number of egg donors now donate through egg-sharing schemes. In return for donating, the cost of their own treatment is subsidised. Although a practical solution for many women, this has implications for the voluntary nature of their donation and for their possible attitudes towards the DCO. It is not unreasonable to ask how voluntary their donation really is given that the eggs are 'donated' in return for discounted treatment, a payment-in-kind. It is also not unreasonable to ask if these women feel coerced or pressurised into donating when they otherwise would not have.

If their fertility treatment is unsuccessful, they may have conflicting feelings towards the DCO, and recipient family, which is unlikely to produce a positive, heathy relationship between DCO, donor and their respective families.

Counselling

Donors need information and counselling about the implications of their donation, and this is even more relevant for those donating under the DDIR who may be identified and contacted by their offspring in the future.

It was previously believed that it was in the donors' best interests to dissociate themselves from the consequences of their donation but this practice was ethically questionable, even before the introduction of the DDIR. Gillon (1994 p611) argues that it is unethical to ask donors to consent to donation "without giving adequate consideration of the consequences". He also comments that gamete donation has implications for the donor's family too, as the donation may result in new family members they know nothing about. The donor may be able to dissociate themselves from the consequences of donation but this may not be as easy for other family members, in particular adolescent children, for whom this may be profoundly disturbing (Gillon 1994 p611).

There is currently only a requirement that "adequate" counselling be offered to donors – there is no obligation for them to accept it (NGDT 2012). The HFEA offers some counselling support to those wishing to re-register as identifiable donors but it is not clear if this support will continue to be available to donors whose DCO are part of

the first cohort born after the introduction of the DDIR (HFEA 2015(b)). There may well be a need in the future for donors to receive counselling around the time their DCO reach 18.

The effect of the DDIR

A study (Murray and Golombok 2000 p2138) of licenced fertility clinics gave the removal of anonymity as a significant deterrent to potential donors, especially younger, childless donors, and this was used as one of the main arguments against the introduction of the DDIR. There was also concern that the number of donors from ethnic minorities would be greatly reduced.

However, figures from the HFEA (2013(b)) show that although there was a decrease in new donor registrations around the time the DDIR was introduced, the number of new sperm and egg donors registered in 2010 was at an all-time high. Overall, the number of women treated with donor insemination has been steadily falling since 1992 (HFEA 2013(c)), possibly due to an increase in the use of ICSI, and the number of patients undergoing IVF/ICSI with donated gametes has also decreased since 2001. This may be due to improvements in assisted reproduction techniques reducing the need for donated gametes, a decrease in the availability of suitable gametes (e.g. ethnically matched gametes) or a decrease in the number of patients choosing to use donated gametes.

The biggest effect of the DDIR will be the chance for identification of and contact with donors by DCO. As yet, no DCO born after the introduction of the DDIR have reached 18 so the full impact of this legislation cannot be assessed.

Contact

Following the introduction of the DDIR, all newly registered UK gamete donors are open-identity donors, which is made clear at the time of donation. It is reasonable to assume that they are at least open to being contacted by their adult DCO in the future, even if they do not wish to reciprocate. The amount of interaction is harder to predict, as is the impact on the donors' families, but Scheib et al (2005 p249) found that donors were positive about forthcoming identity-release and were curious about the DCO. Jadva et al (2011 p642) found that while donors may welcome contact from the DCO they felt it was for the DCO to initiate, possibly reflecting their own view of themselves as a donor rather than a parent.

A small number of Danish open-identity sperm donors were interviewed about their motivation to donate and their views on future contact with their DCO (Russell 2015 pp.30-35). The donors, despite receiving a small payment per donation, generally regarded their main reason for donating as altruistic, as helping people who couldn't have children and giving them the chance to become parents. However, one career-driven donor also "[regarded] being a donor as 'insurance' that my genes carry on". The donors believed that being identifiable was important, that "every child has a right

to know who their donor is" and one donor described how he would feel "cheated" if he was denied the opportunity to find out who his biological father was.

Some thought had been given to the possibility of being contacted by their DCO, once the DCO reached 18, but the general feeling was that it was a long way off. They were open to the idea of being contacted but most felt contact would be limited, perhaps a phone call or exchange of basic information. Only one donor articulated concern about how his partner might feel, the same donor who expressed a desire not to want to "get between a donor child and the dad who raised them". Interestingly, the feeling of being overwhelmed, and of possible regret, was also mentioned in relation to contact, indicating that this can be an intensely emotional topic for donors too.

As well as being intensely emotional for donors, the prospect that the DCO may identify, contact and possibly form a relationship with their donor produces many conflicting emotions for recipient parent(s). Whilst some may be open to the idea of contact between the DCO and donor, others may see it as a threat to their family, much wanted child and possibly to their very identity as parents.

Chapter Five: The Recipient Parent(s)

The decision to use donor gametes is not one which is taken lightly. It allows recipients to become parents and to have "their identity in society enhanced and confirmed by their role in the family unit" (Warnock 1984 p8). The use of donor gametes has "profound social and psychological implications" as the recipient parent(s) must come to terms with the fact they have no genetic link to their child, despite having a nurturing and social one. Accordingly, the HFE Act (1990 (b)) stipulates that people seeking treatment using donated gametes and those seeking to donate should "be given a suitable opportunity to receive proper counselling" about the personal and social implications of their actions.

To tell or not to tell

Despite a number of countries worldwide adopting open-identity donation, the number of recipient parents who choose not to tell their children of their origins is high, at around 75%. The impact of removing donor anonymity is therefore likely to be limited.

The decision to tell is left to the recipient parent(s). Some plan to tell when the children are older but many have no intention of doing so. The process of making the decision to disclose is complex, involving "an interaction between physiological states of the parents and the social, cultural and familial context within which this decision

must be negotiated" (Nachtigall et al 1997 p89). The decision is influenced by the recipient parent(s) beliefs, expectations and experiences.

In one European study (Golombok et al 2002(a) pp.836-7) around 70% of parents had decided not to tell. Their reasons included:

1) The desire to protect the child from distressing information
2) Concern about the impact on family relationships, especially the father-DCO relationship
3) A desire to protect the father, and to a lesser extent, the mother
4) Fear about possible negative reactions of others
5) A belief that there was no need to tell.

In the UK disclosure figures are even lower, with one study showing that only 5% of DI recipients had told their near-adolescent children (Golombok et al 2002(a) p836). A subsequent study (Golombok et al 2006 p1921) found that despite greater encouragement towards disclosure, less than 8% of oocyte recipients and less than 5% of DI recipients had begun to tell their child by the time of the child's third birthday. This is in marked contrast to a previous study (Golombok et al 2004 p448) which found that 50% of recipients planned to tell their child by the time of their 5th birthday. Clearly, the intention to disclose does not always translate into action.

Recipient parents may find it easier to tell their child of their DI origins than to reveal the donor's identity, indicating that it is concerns over revealing the donor's identity, rather than acknowledging the DI, that is problematic. Lalos et al (2007 p1759) found that among the recipient parents who had disclosed the DI to their children, less than

two thirds had also told them about their right to obtain identifying donor information.

The subject of genetic origins and the use of a donor is not easy to broach and many recipient parents may simply choose to avoid the issue altogether (Lycett et al 2005 p811). Additionally, finding an appropriate time to tell may be difficult, especially for heterosexual couples where there is already a parent of each sex present within the family.

By not telling, recipient parents may believe that they are protecting their family, preventing the DCO from developing an emotional relationship with the donor that may threaten the integrity of the family (Gillon 1994 p613). Recipient parents may fear the DCO will reject them, or that the DCO may be rejected or treated differently by other family members if the truth is known.

Leaving the decision to tell to the recipient parents seems far from satisfactory. Frith (2001 p822) argues that "if it is felt that knowledge of one's genetic inheritance is indeed a fundamental right then it might seem unsatisfactory to leave such a decision solely to the parent's discretion". Open-identity donation systems, such as that legislated by the DDIR, can only succeed where the DCO are told of their origins (Shenfield and Steel 1997 pp.393-394). In support of this, the Warnock Report recommended that 'by donation' be added to the birth certificates of DCO, so that they could discover the circumstances of their conception, independently of their parents if necessary (Warnock 1985 pp26 and 38). The recommendation was defeated as it was thought it would cause the DCO unnecessary embarrassment (Morgan and Lee 1990 cited in Frith 2001 p822).

A Dutch study examining the reasons behind recipient parents choosing anonymous or open donors found that the major motive for heterosexual couples choosing an anonymous donor was fear of interference from the donor in their lives. In this study this was felt more by men than women, who were afraid the donor would "negatively influence the child's love for them as social fathers" (Breaeys et al 2005 p822). Concerns about the impact of telling on the recipient father-DCO relationship are often raised, and these concerns still remain for recipient parents who have told the DCO of their origins (Hunter et al 2000 cited in Breaeys et al 2005 p823). Scheib et al (2003 p1121) found the response of family and friends to the disclosure that recipient parents had used open-identity DI was neutral to moderately positive, suggesting that attitudes towards DI are changing and that concerns around open-identity donation are less to do with keeping the use of DI secret and more to do with reducing the risk of interference from the donor into family life.

Conversely, open-identity donation in places like the USA is increasingly popular. It gives recipient parents more information about the donor, both for themselves and to give to the DCO, and DCO have the option of identifying and possibly meeting their donor in the future (Raboy 1993, Cordray 2000, Scheib et al 2000 cited in Scheib et al 2003 p1115). A 2003 study of open-identity donation recipients found that over 80% chose open-identity donation because they believed it was the right thing to do and they wanted their child to be able to access donor information (Scheib et al 2003 p1119). In the same study, recipient parents reported that disclosing had a positive impact on their relationship with their child, creating a "sense of trust in the child". DCO who learn about their origins before adulthood show less resentment towards

their family, although the desire and need to know more about their donor remains (Franz and Allen 2001, Blyth 2002, Shanner and Harris 2002, Lorbach 2003 cited in Scheib et al 2005 p240).

Having access to more donor information, including identifying information, may make it easier for recipient parents to tell their children of their origins. But the converse is also true; it may make recipient parents less likely to tell if they perceive the DCO's desire to contact the donor as a threat to their family relationships. The decision to disclose is likely to be influenced by more than the knowledge that the DCO will be able to, as an adult, identify and contact their donor. The cultural acceptance of (male) infertility, use of DI and acceptance of different family structures (i.e. heterosexual couples, same sex couples and single parents) also affect the decision making process (Frith 2001 pp.820-822; McWhinnie 2001 pp.814-815).

For some recipient parents a belief that being a social parent is more important that being a genetic parent may make it easier to tell the DCO of their origins as the genetically related donor is not seen as a threat. Others may feel that as social parenting is more important there is no need to tell the DCO; identifying the genetic parent would not benefit them. A study by Golombok et al (2005 pp.291-292) found that the families of DCO had more positive parent-child relationships and greater emotional involvement with the DCO than the control group of naturally conceived families, showing the importance of good parenting, be it social or genetic.

There are other advantages for the family in telling. In addition to preserving family structure and cohesion by maintaining trust and openness, recipient parents who had disclosed the information to their children viewed themselves as more competent.

There were fewer severe arguments with their children and fewer conduct problems (Lycett et al 2004 p176). Disclosing the information early, in a positive manner and with the knowledge that donor information is readily accessible, is likely to generate a more positive outcome for all concerned.

Conversely, keeping secret the true origins of the DCO can have a deleterious effect on family relationships (Rowland 1985, McWhinnie 1986 cited in Lycett et al 2005 p811), undermining trust and honesty between parent and child and endangering openness and communication (Clamar 1988 cited in Lycett et al 2005 p811). The breakdown in parent-child relationship may make both the recipient parent(s) and DCO feel more rejected and isolated at a time when family support is likely to be crucial to securing a positive outcome for all.

Accidental disclosure is a major concern for many recipient parents who have not told the DCO of their origins, whether they plan to tell or not. Around 50% of recipients tell a friend or family member the truth about the conception (Golombok et al 1999 p524, Gottlieb et al 2000 p2054) so the chances of accidental disclosure are high.

But the issue is far from straight forward. Recipient parents must attempt to reconcile potential differences between their own interests (not wanting interference from the donor) and those of their child (access to information) to find a solution that puts the well-being of the DCO first (Breaeys et al 2005 p823). Leaving the decision of when and how to tell with the recipient parents gives them some control over the situation but also means that they should and will tell the DCO of their origins, and it assumes that knowing is in the DCO's best interest. It is commonly accepted that whilst truth and honesty are best, they can be painful and damaging. Some children may prefer not to

know; they may be happy and secure within their family, or may fear the consequences of such a revelation. Family relationships are complicated and the impact of such a truth may be far wider than imagined.

Attitudes towards the donor

A reluctance to tell the DCO of their origins does not seem to stem from a negative attitude towards the donor. Many recipient parents are appreciative of and curious about the donor and have a generally positive attitude towards them. Some regret not being able to thank the donor (Vanfraussen et al 2001 p2022). Scheib et al (2003 p1123) found that none "reported being angry, threatened, jealous, or resentful". The donor themselves is not the problem but the threat they may pose to family life is.

A family affair

Before the introduction of the DDIR recipient parents were often advised to keep their use of donated gametes secret from even family and close friends. Many did so, or only shared the knowledge with selected people.

If the truth became more widely known it had effects not only on the DCO, and on the relationship between the DCO and recipient parent(s), but also on the wider family. Some families reacted positively to the discovery but, as has been seen with donors, recipient parents and the DCO themselves, the discovery is not always easy, and creates a myriad of different emotions and reactions.

Chapter Six: The Families

It is easy, and perhaps tempting, to examine DCO, donors and recipient parents either as individual entities or as a trinity. In reality, they exist as part of a wider family or social group, all of which can be affected by the decisions they each make (see Appendix 2 for a family tree showing some of the genetic, legal and social links surrounding the DCO).

Families, in whatever form they come, are important and valued institutions. They are responsible for far more that simply passing down genetic material from generation to generation. Families nurture and protect, teach social behaviours and skills and are the place where "the child develops its own identity and feeling of self value" (Warnock 1984 p8).

The families in particular are often neglected in discussions about the impact of disclosure or non-disclosure. The reactions, or suspected reactions, of immediate family may be very important in the process of disclosure and identifying or contacting the donor.

Where the recipient parents have chosen open-identity donation very few regret their choice and disclosure rates appear to be higher. They are more positive about their use of DI and that their child can obtain the donor's identity and, importantly, disclosure did not have a negative impact on their families (Scheib et al 2003 p1115).

Spouses and partners

UK gamete donors do not need the consent of a current partner in order to donate. Whilst some donors will inform their partners that they are donors, many will not (Sauer et al 1989 cited in Pennings 1996 p1135). A study by Cook and Golombok (1995(b) p954) found that only 21% of sperm donors were concerned about their current or future partner's views on them being donors. Responses to discovering that their partner is a gamete donor are variable, and further complicated by the knowledge that the DCO may contact, and possibly have a relationship with, the donor. Much has been said about the threat that recipient parents may perceive this to be but little has been said about the effect this may have on the donor's partner and family.

"'My wife seems to feel threatened by it and hit the roof when she found out I had told our kids about their half-brothers/sisters….. I think subconsciously she has concerns that family resources would be diverted to these children.'" (Jadva et al 2011 p642).

Siblings

The HFE Act 1990 (1990(a)) specifically requires that the "welfare of any other child who may be affected by the birth" be taken into account before agreeing to provide treatment. Traditionally 'any other children' is taken to mean 'any other children of

the recipient' but following the change to open-identity donation it can be argued that it should also include 'any other children of the donor'.

DCO have three potential sets of siblings. They have 'social siblings within the recipient family' (who may or may not be genetically related to the DCO), 'social siblings within the donor family' (who are the children born to the donor naturally, not as a result of gamete donation) and 'donor-siblings' (who are DCO in other recipient families who share the same donor).

Social siblings within the recipient family

The effect on the 'social siblings within the recipient family' of the DCO identifying and contacting their genetic family and half-siblings is variable and ranges from relaxed and pleased to indifferent, jealous and threatened (Blyth 2012(b)). Even if the DCO's discovery of their genetic family is supported by their recipient family it evidently has an impact on the relationships with social-recipient siblings, and may also change the dynamics of the relationship between the social-recipient siblings and their parents. This may be particularly evident in families with children from more than one donor, where not all of the donors reciprocate contact.

Social siblings within the donor family

This group of siblings is probably the most commonly overlooked, and is also the group with the fewest rights regarding the need-to-know or opportunities to contact DCO.

Although they are genetically related to the DCO and share the same donor of genetic material (albeit one via gamete donation) they have no right to initiate contact with the DCO. Additionally, there is no straightforward way for the DCO to contact them (private communication 2015).

No attention appears to have be paid to their potential need to know their genetic siblings to form a sense of their own identity, or to their potential curiosity about other siblings. Some donors recognise the needs of their naturally conceived children: "'The basis of making contact was not so much for me to personally meet my donor child and for her to know me as her genetic father, but rather for my 10 year old non-donor daughter to one day meet her donor half-sibling and form a relationship'" (Jadva et al 2011 p643).

This recognition does not appear to be universal, and is perhaps less likely if the donor has kept the donation secret from their partner and family. If the donor reciprocates contact with the DCO there is still no guarantee that this contact will include, directly or indirectly, the donor's naturally conceived children.

Additionally, as there is nothing to compel the donor to tell their family of their donation, the first the social siblings within the donor family may know of this is when the DCO make contact. This has the potential to create a range of feelings, from pride through to a deep sense of betrayal.

Donor Siblings

Scheib et al (2005 p246) found that DCO were between moderately and very interested in having contact with donor-siblings. Many recipient parents also search for their child's donor-siblings, mostly because they are curious but also to enhance the DCO's sense of identity (Freeman 2009 p507).

Contact between DCO and donor-siblings is likely to become increasingly common following the introduction of the DDIR but there has been little research into the experiences of DCO searching for and contacting donor-siblings. The potential for parents and children to form relationships with members of families who share the same donor is a significant consequence of the removal of donor anonymity that has yet to receive adequate attention. Jadva et al (2010 pp.526-531) found that the two most common reasons for DCO to search for donor-siblings were curiosity (94%) and to help develop their sense of self (52%). This cohort of DCO reported that their search for donor-siblings had a neutral to positive impact on their relationship with their recipient parent(s) and that overall the experience of meeting donor-siblings was positive. However, it is important to note that the numbers of donor-siblings contacted in this study was low and much larger donor-sibling groups have been reported (a donor-sibling group of 150 has been identified in the US (Mroz 2011)).

Whilst contact with donors and donor-siblings can be a positive experience the discovery of large numbers of donor-siblings can be a negative one, especially if not expected. The concept of family, already non-traditional, is further distorted for DCO discovering they have large numbers of donor-siblings. Overall it appears that little

thought has been given to how to prepare DCO identifying and contacting donor-siblings and more work is needed in this area.

The wider family

Establishing contact with the donor will, in some cases, mean that contact can be established with the wider family. Contact from the DCO may be welcomed by the donor's family.

"'My mom, who has no grandchildren, is thrilled with these additions to the family. My sister enjoys being an aunt….. I am very happy to know these kids and consider myself very fortunate'" (Jadva 2011 p643).

Whilst this will undoubtedly be a positive experience for some, it will not be for all and it may increase the sense of threat to family life felt by recipient parents and possibly by the DCO themselves. It is important to remember that wanting to know more about the donor does not automatically translate into wanting a relationship with the donor/donor family.

This may be difficult for donor families who do want a relationship with the DCO, especially as unlike recipient grandparents or other relatives they have no legal right to contact with the DCO.

The wider family is not limited to the wider family of the donor. Jadva et al (2010 p531) found that a trigger for many DCO searching for their donor-siblings and donors

was having children themselves. The importance of knowing one's genetic identity appears to go beyond the needs of the DCO and includes others related to the DCO.

Spider-web families

Simply looking at the consequences of revealing, or concealing, the identity of the donor for the DCO, donor, recipient parent(s) and wider family unduly simplifies the relationships that exist between each and all of them (Snowdon and Snowdon 1994 p603). The branches of the spider-web families are based on both direct and indirect genetic, social and legal links and "shared understandings and experiences" (Freeman at al 2009 p514).

DCO (and the other children of the donor and recipient parent(s)) live in fragile webs of family and social relationships, which may be disrupted, or even broken, by the addition of new family members. Whilst the addition of family members may be positive it is important to remember that it will not be so in all cases, and that it may do irrevocable harm both to individual family members and to family relationships.

There is no guarantee that genetic knowledge will equate to a greater happiness or sense of fulfilment; at its most basic level it is simply information but within the family it becomes "deep knowledge about one's kinship network and also about one's self" (Smart 2010). Thus it takes on great power and must be revealed and used responsibly.

The importance of counselling and support is becoming increasingly recognised. Counselling is offered to donors and recipients around the time of donation and

treatment but many of the issues surrounding donation may not arise until years later, most commonly when the DCO wishes to access more information. The HFEA (2015(b)) is piloting a support and intermediary service for people affected by post-donation issues, aimed primarily at donors and DCO, to support them through the process and implications of identification and contact. As the first cohort of DCO born after the DDIR will not be able to contact their donors until 2024, it will not be until then that the full implications of the DDIR, for donor, recipient parent(s), DCO and the wider family, will be felt but ensuring adequate support is in place before then is vital. Whilst knowing one's genetic origins is important, it must also be stressed that genetic ties alone do not make a family.

Chapter 7: Conclusion

The importance of the DCO's right-to-know is increasingly being recognised by recipient parents, but translating this understanding into action is problematic. Educating recipient parents as to why and how to disclose, in addition to giving them information to help answer the DCO's questions about the donor is likely to help increase disclosure rates (Scheib et al 2003 p1116).

The provision of counselling appears to be key to successful disclosure and ensuring a positive outcome for all involved. In Sweden, parents are counselled about disclosure and are expected to tell their DCO of their origins. A Swedish study undertaken after open-identity donation was legislated for showed that although relatively few recipient parents had told their DCO of their origins (11% of parents had told, 41% were planning to tell, 11% were undecided) disclosure rates were increasing (Gottlieb et al 2000 p2053).

Respecting the "child's autonomy" and maintaining the openness and truthfulness that are accepted as important for family relationships are "ethical demands, which [are] almost impossible to convert into a legal obligation" (Thévoz 1996 cited in Turkmendag et al 2008). Although the DDIR ensures that DCO can identify their donors once they reach 18, there is no legislation that ensures DCO are told of their origins; if they are not told they cannot exercise their right-to-know. Low disclosure rates, in combination with the DDIR, suggest that attitudes towards the acceptance and use of donor gametes still have a way to go – whilst it is accepted that the DCO have a right-

to-know, informing them of their origins is clearly another matter. Unless legislation is introduced to ensure that DCO are told of their origins we must accept that recipient parents will continue to act paternalistically to protect their children, basing their decisions on whether, when and how to tell on what they believe is best for the DCO. They must balance their welfare-based decisions, which are likely to include the welfare of the wider family, with autonomy-based decisions that favour telling the DCO of their origins because they have a right-to-know.

The importance and significance of the right-to-know have also been questioned. Whilst it is undoubtedly true that people have a right not to be deceived, the automatic assumption between knowing about genealogical kin and the creation of a relationship with them is less clear. Marilyn Strathern (1999 cited in Smart 2010) asks "Is it possible to want to 'know about' a father and yet not want to 'relate' to him in a substantive way? If so, are we in danger of conflating these two components when it comes to contemporary interventions in family life?" Similarly Fortin (2009 p338) comments that an increasing emphasis is being placed on the importance of biological ties, causing the right-to-know one's genetic parents to develop into a "right to be *with* one's parents", a marked difference from the right to identify one's genetic parents granted under Article 8 of the Human Rights Act (1998 HRA(b)). Human rights law does not support the idea that DCO have both a right to identify their donor and to know and have contact with them (Fortin 2009 p347). The DDIR is simply a disclosure of information about the donor. It is not, and should not be considered to be, a way of creating a 'new family'. Turkmendag et al (2008) argue that where anonymity is removed, DCO may contact their donors "not necessarily because of a

'natural' desire to know their origins, but because such a desire is constructed, recognised and legitimized in the law".

Although some DCO who contact their donors and donor-siblings will go on to develop meaningful relationships not all will, and there is a danger that a new normative standard is being created "that insists, for children at least, that knowing about is not enough and that emotional and physical closeness is also required" (Smart 2010).

Conflating the right-to-know with developing a relationship with the donor increases the strain felt by recipient families, and by donors and DCO themselves, and may in fact deter DCO from exercising their right-to-know.

Honouring the rights of all the parties involved in and affected by gamete donation is simply not possible. The best that can be hoped for is a compromise, in which the rights of the individuals are carefully and fairly balanced against each other to decide whose rights are more in need of protection. When this is done, it becomes evident that the DCO's right-to-know cannot and should not be given "absolute priority" (Besson 2007 p156, Fortin 2009 p347).

Whilst the DCO's right-to-know does not have absolute priority, they should not be deceived as to their origins, nor should DCO be denied the opportunity to find out more about their genetic identity. As Scott Baker J (*Re R* [2002]) said "A human being is a human being whatever the circumstances of his conception and an AID child is entitled to establish a picture of his identity as much as anyone else".

The DCO right-to-know is important, and when the interests and rights of all the parties are given careful consideration it is rightly the ruling bioethical principle behind the DDIR, but insufficient consideration has been given to the rights of others affected by the donation, in particular the rights of the donor and donor's naturally conceived children. Their wishes, needs and rights will be made increasingly known after 2024, when the first cohort of DCO are able to contact their donors under the DDIR. They too have a right to not to be deceived, a right to know their families and to understand their identities. The same arguments that have been used to support the rights of the DCO can often be used to support those same rights in the other interested parties. It is dangerous and foolhardy to simply consider the rights of the DCO as a stand-alone entity. Just as the family members are linked by their genetics, the law and their social environment, so too are their rights interlinked.

The right-to-know is now enshrined in law, but it is important to remember that there is a difference between a *need* to know and a *desire* to know, between accessing information and creating a new family and between understanding our past and shaping our future.

'To whom related, or by whom begot?'

Alexander Pope,

Elegy to the Memory of an Unfortunate Lady.

Word count: 16133

Appendix 1 – Laura's story

This hypothetical case study has been designed to illustrate some of the issues raised by gamete donation and the DDIR, and to demonstrate the complexity of the spider-web families created by using donor gametes.

Michael Smith is a 34 year-old teacher. He is married, with one child. Michael decided to become a sperm donor after a close friend suffered infertility problems. Michael and Margaret, his wife, are both supportive of sperm and egg donation. They have several friends who have needed help to conceive and believe gamete donors are truly altruistic. Despite this, Michael did not tell Margaret of his decision, fearing she wouldn't approve.

In 2005, Michael donated sperm through a local licenced clinic he found through the National Gamete Donation Trust. Michael donated after the introduction of the DDIR, as an open identity donor. He is aware of his legal position but has given little consideration to the prospect of any children born as a result of his donation contacting him in the future – 18 years is a long way off. Michael and Margaret continue with their lives and have 2 more children. Michael occasionally thinks about his donation but as the years pass he thinks about it less and less.

The clinic use Michael's donation to help Edward and Mary Jones conceive a baby girl, Laura. Initially, both Edward and Mary had decided that they would tell Laura of her

origins, but after she is born and people comment what a good father Edward is and how much Laura looks like him, they begin to have doubts. They were counselled at the clinic about disclosing the truth and they are aware that Laura, once she reaches 18, can contact her donor, but they feel that she is happy and stable and it would only cause distress and upset to tell her. Edward is particularly reluctant to tell her as he feels they have a special father-daughter bond and he is concerned that he would be usurped by the donor. They know that the donor has no legal rights over Laura and they, in return, want nothing from him.

Laura is a happy, healthy child and has no idea of her origins until she reaches 15, when Edward finally agrees to tell her the truth.

Laura takes the news badly and is furious with her parents. They are confused, hurt and afraid that they may lose their daughter and that she may prefer her unknown donor to them.

Laura feels let down and betrayed by Mary and Edward. She still loves them and considers Edward her father but she is struggling to understand why they kept this from her – her trust in her family has been badly damaged. Although her maternal family are supportive and loving, her paternal family have been more distant since the news and she feels rejected, confused and hurt.

The wider family are shocked that Edward and Mary had kept such a big secret from them. Mary's family is supportive; Laura is one of the family, no matter who her genetic father, and this does not change how they feel about her. They re-assure Mary and Edward that Laura's desire to know about and have contact with her donor does not mean that she is rejecting them, or seeking to replace them, merely that she's

curious and wants to know more. Privately, they are concerned that the donor may seek to be a father to Laura and take her away from the family.

Edward comes from a family with strongly held religious beliefs and they find the news harder to take. Not only are they hurt that this was kept from them, they also feel disapproval that such a method was used in the first place. They struggle to reconcile their feelings towards Edward and Mary and particularly towards Laura and there is a period of coolness between them. They do not want Laura to find out about her donor.

Laura herself is curious about her donor. When she reaches 16 she accesses the non-identifying information about him and at 18 she decides to contact him. She is not looking for a replacement father, she would just like more information about Michael and a family that she has never met.

In 2024 Laura makes contact with Michael by letter. He is shocked; he has not thought about his donation for so many years he had almost forgotten about it. Laura's letter does not say what she wants, only that she is his daughter and would like to meet him.

Michael still has not told Margaret that he is a sperm donor. He made his donation purely altruistically to help somebody else become a parent. He does not want another child. He wishes Laura no harm but sees her as a potential threat to his existing family.

Margaret finds Michael's letter from Laura and is devastated. She feels betrayed, not because Michael donated sperm but because he did not tell her. Her sense of betrayal deepens when she discovers Michael knew that the donation had resulted in a

successful pregnancy. She is curious about Laura but fears for her family. She does not know what Laura hopes to gain by contacting Michael.

After Laura makes contact, Michael and Margaret decide to tell their children about her. The children feel a similar sense of betrayal to Laura and Margaret; they have been lied to and their trust has been damage. Their feelings regarding Michael being a donor are mixed; they are proud but also hurt that they were never told, and angry because if Laura had not made contact they would never have known they have a half-sister. However, they have an otherwise strong and open family relationship and this anger quickly turns to curiosity about Laura. They want to know more about her, but they don't want another sister.

Margaret too is curious so Michael decides to reciprocate contact.

Michael and Margret decide to tell the wider family. Their feelings are mixed but most of the anger felt is because Michael was not open and honest, rather than because he was a sperm donor. They too are curious to know about Laura but they advise Michael and Margaret to continue cautiously. They ask them to think about how Laura's parents may be feeling and advise Michael to make it very clear to Laura exactly how he fits into her life.

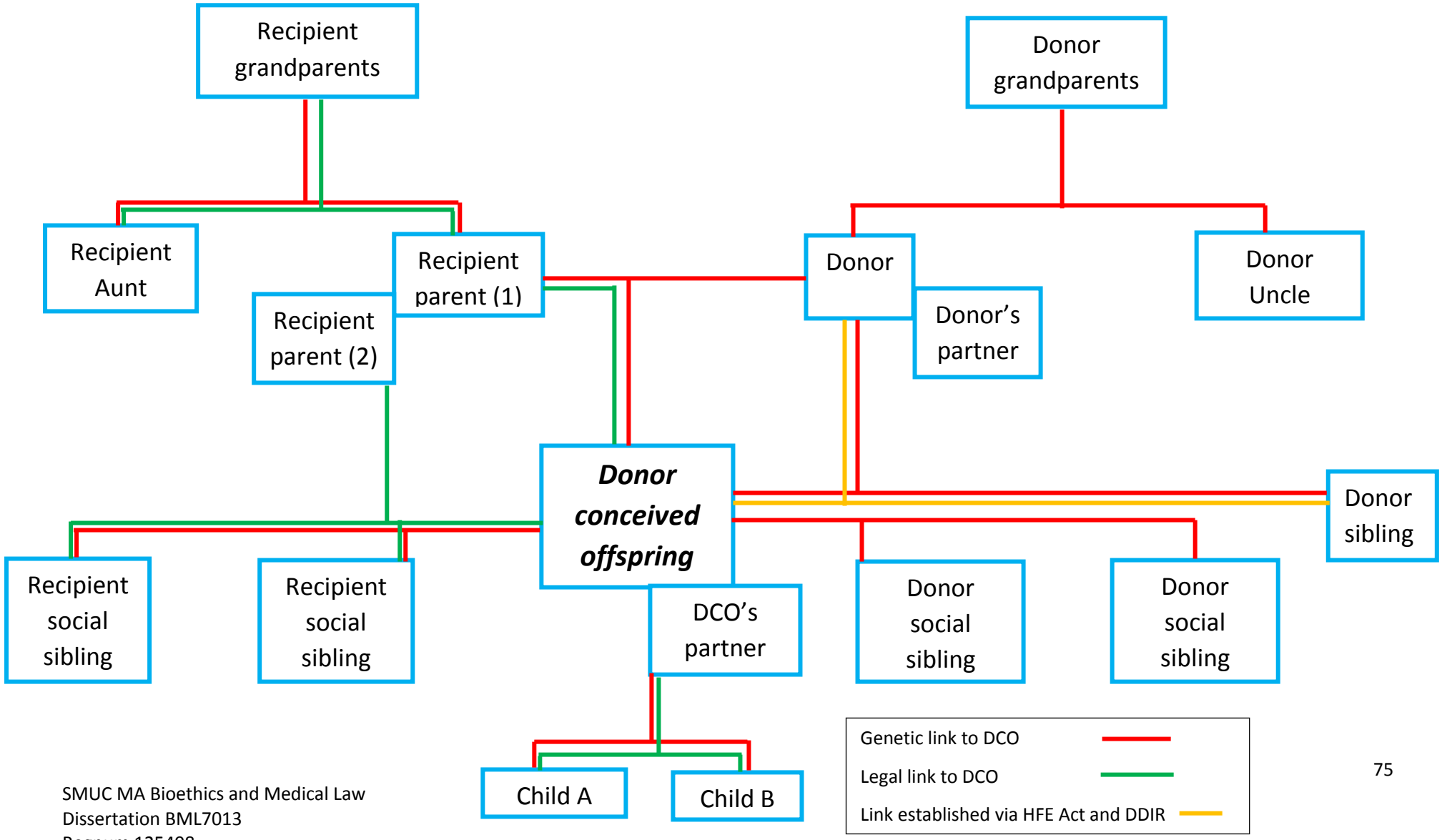
After discussion with Margaret, their children and the wider family, Michael contacts Laura. He is very clear that he does not consider himself her father and does not want to be her father, but he is her donor and if he can help her 'fill in the gaps' he will.

Laura is thrilled – after making contact she had worried that Michael might consider himself her father, when all she really wants at this stage is information.

Edward and Mary are relieved. They have been rebuilding their relationship with Laura and are now reassured that she considers them to be her parents. They can now allow themselves to feel excited for Laura, and for themselves, as they discover more about the donor who helped them to have a family.

The wider families have, to varying degrees, come to terms with the situation and most are pleased, although some (notably Michael's parents) still do not wish to have anything to do with discussions about the donation, donor, or the donor's family.

Appendix 2 - A Donor Conceived Family Tree



Bibliography

Almond, B, 1994. “Chapter 45: Individual rights in the healthcare relationship”, in R. Gillon (ed.) 1994. *Principles of Health Care Ethics*. Chichester: John Wiley & Sons.

BMA Ethics Department. 2004. *Medical Ethics Today: The BMA’s Handbook of Ethics and Law (second edition).* London: BMJ Books.

Brazier, M., Cave, E. 2011. *Medicine, Patients and the Law: Fifth Edition*. London: Penguin Books.

Dancy, J. 1993. “An ethic of prima facie duties”, in P. Singer (ed.) 1993. *A Companion to Ethics*. Oxford: Blackwell Publishers, pp.219-229.

Frith, L. 2001. “Gamete Donation and Anonymity: The Legal and Ethical Debate”, *Human Reproduction*, **16**, 5, pp.818-824.

Gewirth, A., 1995. “Rights”, in T. Honderich (ed.) 1995. *The Oxford Companion to Philosophy*. Oxford: Oxford University Press, p.776.

R. Gillon (ed.) 1994. *Principles of Healthcare Ethics*. Chichester: John Wiley & Sons Ltd.

Golombok, S., Brewaeys, A., Giavazzi, M., Guerra, D., MacCallum, F., Rust, J. 2002(a). “The European study of assisted reproduction families: the transition to adolescence”, *Human Reproduction*, **17**, 3, pp.830-840.

Herring, J. 2012. *Medical Law and Ethics: 4th Edition*. Oxford: Oxford University Press.

Hewitt, G. 2002. “Missing links: Identity issues of donor conceived people”, *Journal of Fertility Counselling*, **9**, pp.14-20.

Kirkman, M., Bourne, K., Fisher, J., Johnson, L., Hammarberg, K. 2014. “Gamete donors’ expectations and experiences of contact with their donor offspring”, *Human Reproduction,* **29**, 4, pp.731-738.

Lycett, E., Daniels, K., Curson, R., Golombok, S. 2005. “School-aged children of donor insemination: a study of parents disclosure patterns”, *Human Reproduction*, **20**, 3, pp.810-819.

McWhinnie, A. 2001. “Gamete donation and anonymity: should offspring from donated gametes continue to be denied knowledge of their origins and antecedents?”, *Human Reproduction*, **16**, 5, pp.807-817.

Murray, C., Golombok, S., 2000. “Oocyte and semen donation: a survey of UK licences centres”, *Human Reproduction*, **15,** 10, pp.2133-2139.

Private communication. 2015. Email from Rosette Wotton, HFEA.

Russell, H. 2015. “Who becomes a sperm donor?”, *The Times Magazine.* 17th May, pp.30-35.

Scheib, J., Riordan, M., Rubin, S. 2003. “Choosing identity-release sperm donors: the parents’ perspective 13-18 years later”, *Human Reproduction*, **18**, 5, pp.115-1127.

Scheib, J., Riordan, M., Rubin, S. 2005. “Adolescents with open-identity sperm donors: reports from 12-17 year olds”, *Human Reproduction*, **20**, 1, pp.239-252.

Snowdon, R., Snowdon, E. 1994. “Ethical problems in infertility treatment” in R. Gillon (ed.) 1994. *Principles of Healthcare Ethics*. Chichester: John Wiley & Sons.

Turner, A., Coyle, A. 2000. “What does it mean to be a donor offspring? The identifying experiences of adults conceived by donor insemination and the implications for counselling and therapy”, *Human Reproduction*, **15**, 9, pp.2041-2051.

Warnock, M. 1985. *A Question of Life: The Warnock Report on Human Fertilisation and Embryology*. Oxford: Blackwell Publishers.

Warnock, M. 1987. "The good of the child", *Bioethics*, **2**, pp.141-155.

Warren, M. 1993. "Abortion", in P. Singer (ed.) 1993. *A Companion to Ethics*. Oxford: Blackwell Publishers, pp.303-314.

Internet sources

Access to Medical Reports Act 1988: Chapter 28, Section 7. HMSO: London.

<http://www.legislation.gov.uk/ukpga/1988/28> (visited 6/11/2014).

Adoption Act 1976: Chapter 36, Part 5, Section 51. HMSO: London.

<http://www.legislation.gov.uk/ukpga/1976/36> (visited 21/10/2014 and 2/7/2015).

Adoption and Children Act 2002: Part 1, Chapter 3, Section 60. HMSO: London.

<http://www.legislation.gov.uk/ukpga/2002/38/section/60> (visited 2/7/2015).

Agarwal, A., Allamaneni, S. 2007. "Chapter 6: Artificial Insemination", in T. Falcone and W. Hurd (eds.) 2007. *Clinical Reproductive Medicine and Surgery.* Philadelphia: Mosby, Inc.

<http://www.clevelandclinic.org/ReproductiveResearchCenter/docs/agrach019.pdf> (visited 15/10/2014).

Almack, K. 2006. "Seeking sperm: accounts of lesbian couples reproductive decision making and understandings of the needs of the child", *International Journal of Law, Policy and the Family*, **20**, 1, pp.1-22.

<http://www.lexisnexis.com.stmarys.idm.oclc.org/uk/legal/results/enhdocview.do?docLinkInd=true&ersKey=23_T22340279564&format=GNBFULL&startDocNo=0&resultsUrlKey=0_T22340279566&backKey=20_T22340279567&csi=302251&docNo=1&scrollToPosition=0> (visited 20/5/2015).

BAAF. 2014. “All about adoption”, *British Association for Adoption and Fostering*.

<http://www.baaf.org.uk/info/adoption#tell> (visited 6/7/2015).

Barton, M., Walker, K., Wiesner, B. 1945. “Artificial Insemination”, *British Medical Journal*, **1**, pp.40-43.
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2056529/?page=1http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2056529/?page=1> (visited 15/10/2014).

BDM. 2015. “Central Register: Births Deaths Marriages Victoria”, *Department of Justice and Regulation.*

<http://www.bdm.vic.gov.au/home/births/donor+treatment+registers/central+register.html> (visited 2/7/2015).

Bellis, M., Hughes, K., Hughes, S., Ashton, J. 2005. “Measuring paternal discrepancy and its public health consequences”, *Journal of Epidemiology and Community Health*, **59**, 9, pp.749-54.

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1733152/pdf/v059p00749.pdf> (visited 15/6/2015).

Be My Parent. 2012(a). “What is life story work and why is it important?”

<https://www.bemyparent.org.uk/info-for-families/your-questions/what-is-life-story-work-and-why-is-it-important,128,AR.html> (visited 6/7/2015).

Be My Parent. 2012(b). “What is direct and indirect contact?”

<https://www.bemyparent.org.uk/info-for-families/your-questions/what-is-direct-and-indirect-contact,129,AR.html> (visited 6/7/2015).

Besson, S.2007. “Enforcing the child’s right to know her origins: contrasting approaches under the Convention on the Rights of the Child and the European Convention on Human Rights”, *International Journal of Law, Policy and the Family*, **21**, 2, pp.137-159.

<http://heinonline.org.stmarys.idm.oclc.org/HOL/Page?handle=hein.journals/intlpf21&id=141&collection=journals&index=journals/intlpf> (visited 22/7/2015).

Births and Deaths Registration Act 1953: Part 1, Section 10. HMSO: London.
<http://www.legislation.gov.uk/ukpga/Eliz2/1-2/20/section/10/enacted> (visited 18/7/2015).

Blyth, E., Frith, L. 2008. "The UK's Gamete Donor 'Crisis' – a Critical Analysis", *Critical Social Policy,* **28**, 1, 74, p74-95.
<http://csp.sagepub.com.stmarys.idm.oclc.org/content/28/1/74.full.pdf+html> (visited 15/6/2015).

Blyth, E. 2012(a). "Access to genetic and birth origins information for people conceived following third party assisted conception in the United Kingdom", *International Journal of Children's Rights*, **20**, 2, pp.300-318.
<http://heinonline.org.stmarys.idm.oclc.org/HOL/Page?handle=hein.journals/intjchrb20&div=23&collection=journals&set_as_cursor=5&men_tab=srchresults&terms=Blyth,%20Eric&type=matchall> (visited 13/7/2015).

Blyth, E. 2012(b). "Discovering the 'Facts of Life' following anonymous donor insemination", *International Journal of Law, Policy and the Family*, **26**, 2, pp.143-161.
<http://www.lexisnexis.com.stmarys.idm.oclc.org/uk/legal/results/enhdocview.do?docLinkInd=true&ersKey=23_T22322084933&format=GNBFULL&startDocNo=0&resultsUrlKey=0_T22322084935&backKey=20_T22322084936&csi=302251&docNo=2&scrollToPosition=0> (visited 1/10/2014).

BMJ. 1960. "Human artificial insemination: Feversham Committees Report", *British Medical Journal,* **2**, pp.379-380.
<http://www.bmj.com.stmarys.idm.oclc.org/content/2/5195/379.full.pdf+html> (visited 20/5/2015).

Breaeys, A., de Bruyn, J., Louwe, L., Helmerhorst, F. 2005. "Anonymous or identity registered sperm donors? A study of Dutch recipient's choices", *Human Reproduction*, **20**, 3, pp.820-824.

<www.humrep.oxfordjournals.org/content/20/3/820.full.pdf+html> (visited 30/9/2014).

Campbell, C. 2006. "Donor Identity Rules and IVF", *The Times - Letters to the Editor.* 21st September.

<http://www.thetimes.co.uk/tto/opinion/letters/article2069208.ece> (visited 29/6/2015).

Carsten, J. 2000. "Knowing where you've come from: ruptures and continuities of time and kinship in narratives of adoption", *Journal of the Royal Anthropological Institute*, **6**, 4, pp.687-703.

<http://web.b.ebscohost.com.stmarys.idm.oclc.org/ehost/detail/detail?vid=2&sid=59c4d6f9-463f-42a3-9491-f3ef4784368f%40sessionmgr112&hid=118&bdata=JnNpdGU9ZWhvc3QtbGl2ZQ%3d%3d#db=aph&AN=4031000> (visited 14/7/2015).

Cook, R., Golombok, S., Bish, A., Murray, C. 1995(a). "Disclosure of donor insemination: parental attitudes", *American Journal of Orthopsychiatry,* **65**, 4, pp.549-559.

<http://web.b.ebscohost.com.stmarys.idm.oclc.org/ehost/pdfviewer/pdfviewer?vid=2&sid=8e5fef34-46fd-4358-892c-7a2c2d397507%40sessionmgr113&hid=106 > (visited 20/5/2015).

Cook, R., Golombok, S. 1995(b). "A survey of semen donation: phase II – the view of the donors", *Human Reproduction*, **10**, 4, pp.951-959.

<https://journalarchives-jisc-ac-uk.stmarys.idm.oclc.org/media/pdf/oup/journals/humrep/humrep_10_4.pdf/10-4-951.pdf> (visited 29/6/2015).

Daniels, K., Lewis, G., Gillett, W. 1995. "Telling donor insemination offspring about their conception: the nature of couple's decision making", *Social Science and Medicine,* **40**, 9 pp.1213-1220.

<http://www.sciencedirect.com.stmarys.idm.oclc.org/science/article/pii/027795369400251N> (visited 21/5/2015).

Davies, R. 2010. "Grandparents and their status in family law", *Family Law Week.*

<http://www.familylawweek.co.uk/site.aspx?i=ed54992> (visited 6/7/2015).

DIA. 2015. "Human Assisted Reproductive Technology (HART) Register", *The Department of Internal Affairs*.

<http://www.dia.govt.nz/diawebsite.nsf/wpg_URL/Services-Births-Deaths-and-Marriages-Human-Assisted-Reproductive-Technology-(HART)-Register?OpenDocument#three> (visited 2/7/2015).

Education Act 1996: Part X, Chapter VI, Section 576. HMSO: London.

<http://www.legislation.gov.uk/ukpga/1996/56/section/576> (visited 6/5/2105).

Family Law Reform Act 1987: Chapter 42, Part 4, 27 (1)-(3). HMSO: London.

<http://www.legislation.gov.uk/ukpga/1987/42> (visited 16/10/2014).

Fortin, J. 2009. "Children's right to know their origins – too far, too fast?", *Child and Family Law Quarterly,* **21**, 3, pp.336-355.

<http://heinonline.org.stmarys.idm.oclc.org/HOL/Page?handle=hein.journals/chilflq21&div=25&collection=journals&set_as_cursor=19&men_tab=srchresults&terms=Fortin,%20Jane&type=matchall> (visited 22/7/2015).

Freeman, T., Jadva, V., Kramer, W., Golombok, S. 2009. "Gamete donation: parents' experiences of searching for their child's donor siblings and donor", *Human Reproduction*, 24, **3**, pp.505-516.

<http://humrep.oxfordjournals.org/content/24/3/505.full.pdf+html> (visited 29/6/2015).

Gallagher, J. 2014. “UK sperm bank opens for business”, BBC News.

<http://www.bbc.co.uk/news/health-29815524> (visited 24/6/2015).

Golombok, S., Murray, C., Brinsden, P., Abdalla, H. 1999. “Social versus biological parenting: family functioning and the socioemotional development of children conceived by egg or sperm donation”, *Journal of Child Psychology and Psychiatry*, **40**, 4, pp.519-527.

<http://web.b.ebscohost.com.stmarys.idm.oclc.org/ehost/pdfviewer/pdfviewer?vid=2&sid=eeefe52f-fb87-472e-b559-322d1f4194bb%40sessionmgr113&hid=118> (visited 15/6/2015).

Golombok, S., MacCallum, F., Goodman, E., Rutter, M. 2002(b). “Families with children conceived by donor insemination: a follow-up at age 12”. *Child Development,* **73**, 3, pp.952-986.

<http://web.a.ebscohost.com.stmarys.idm.oclc.org/ehost/pdfviewer/pdfviewer?sid=3e7584be-9ab5-498b-ba80-cac9cad9871a%40sessionmgr4004&vid=3&hid=4204 > (visited 15/6/2015).

Golombok, S., Lycett, E., MacCallum, F., Jadva, V., Murray, C., Abdalla, H., Jenkins, J., Magara, R, Rust, J. 2004. “Parenting infants conceived by gamete donation”, *Journal of Family Psychology,* **18**, 3, pp.443-52.

<http://web.b.ebscohost.com.stmarys.idm.oclc.org/ehost/pdfviewer/pdfviewer?vid=2&sid=5d23e267-cfcd-4c28-906c-0dff4563e028%40sessionmgr111&hid=118> (visited 15/6/2015).

Golombok, S., Jadva, V., Lycett, E., Murray, C., MacCallum, F. 2005. “Families created by gamete donation: follow-up at age 2”, *Human Reproduction,* **20**, 1, pp.286-293.

<http://humrep.oxfordjournals.org/content/20/1/286.full.pdf+html> (visited 5/11/2014).

Golombok, S., Murray, C., Jadva, V., Lycett, E., MacCallum, F., R, Rust, J. 2006. “Non-genetic and non-gestational parenthood: Consequences for parent-child relationships and the psychological well-being of mothers, fathers and children at age 3”, *Human Reproduction*, **21**, 7, pp.1918-24.

<http://humrep.oxfordjournals.org/content/21/7/1918.full.pdf+html> (visited 15/6/2015).

Gottlieb, C., Lalos, O., Lindblad, F. 2000. “Disclosure of donor insemination to the child: the impact of Swedish legislation on couples’ attitudes”, *Human Reproduction,* **15**, 9, pp.2052-2056.

<http://humrep.oxfordjournals.org/content/15/9/2052.full.pdf+html> (visited 15/6/2015).

HLC. 2015. “Access to donor information around the world”, *Health Law Central.*

<http://www.healthlawcentral.com/assistedreproduction/donorconception/international-laws-access-donor-information/> (visited 2/7/2015).

House of Commons Science and Technology Committee. 2005. *Human Reproductive Technologies and the Law: Fifth Report of Session 2004-5, Volume 1,* paragraph 152.

<http://www.publications.parliament.uk/pa/cm200405/cmselect/cmsctech/7/706.htm#a21> (visited 13/7/2015).

HSCIC. “Hereditary medical conditions”, *Health and Social Care Information Centre*.

<http://www.hscic.gov.uk/article/1801/Hereditary-Medical-Conditions> (visited 7/7/2015).

Human Fertilisation and Embryology Act 1990(a): Section 28. HMSO: London.

<http://www.legislation.gov.uk/ukpga/1990/37/section/28> (visited 16/10/2014).

Human Fertilisation and Embryology Act 1990(b): Section 13(5). HMSO: London.

<http://www.legislation.gov.uk/ukpga/1990/37/section/13> (visited 19/10/2014).

Human Fertilisation and Embryology Act 1990(c): Section 13(6) and Schedule 3. HMSO: London.

<http://www.legislation.gov.uk/ukpga/1990/37/section/13>
<http://www.legislation.gov.uk/ukpga/1990/37/schedule/3> (visited 6/11/2014).

Human Fertilisation and Embryology Act 2008: Section 23. HMSO: London.

<http://www.legislation.gov.uk/ukpga/2008/22/section/23> (visited 8/7/2015).

Human Fertilisation and Embryology Authority. 2003. "Code of Practice: 6th Edition". HFEA: London.

<http://www.hfea.gov.uk/docs/Code_of_Practice_Sixth_Edition.pdf> (visited 19/10/2014).

Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004. HMSO: London.

<http://www.legislation.gov.uk/uksi/2004/1511/contents/made> (visited 16/10/2014).

Human Fertilisation and Embryology Authority. 2005. "Who are the donors?: An HFEA analysis of donor registrations and use of donor gametes over the last 10 years". HFEA: London, pp.5-7.

<http://www.hfea.gov.uk/docs/Who_are_the_donors_factsheet.pdf> (visited 5/11/2014).

Human Fertilisation and Embryology Authority. 2012(a). "Sperm donation eligibility".

<http://www.hfea.gov.uk/sperm-donation-eligibility.html> (visited 20/5/2015).

Human Fertilisation and Embryology Authority. 2012(b). "Egg donation and egg sharing".

<http://www.hfea.gov.uk/egg-donation-and-egg-sharing.html> (visited 14/7/2015).

Human Fertilisation and Embryology Authority. 2012(c). "Your legal responsibilities as a sperm, egg or embryo donor".

<http://www.hfea.gov.uk/1972.html> (visited 20/5/2015).

Human Fertilisation and Embryology Authority. 2012(d). "Talk to your child about their origins".

<http://www.hfea.gov.uk/116.html> (visited 20/5/2015).

Human Fertilisation and Embryology Authority. 2013(a). "Fertility Treatment in 2013: Trends and Figures".
<http://www.hfea.gov.uk/docs/HFEA_Fertility_Trends_and_Figures_2013.pdf> (visited 13/5/2015).

Human Fertilisation and Embryology Authority. 2013(b). “Donor conceptions – births and children”.

<http://www.hfea.gov.uk/donor-conception-births.html> (visited 15/5/2015).

Human Fertilisation and Embryology Authority. 2014(a). “How legislation on fertility treatment developed”.

<http://www.hfea.gov.uk/1319.html> (visited 7/10/14).

Human Fertilisation and Embryology Authority. 2013(c). “New donor registrations”.

<http://www.hfea.gov.uk/3411.html> (visited 6/10/2014).

Human Fertilisation and Embryology Authority. 2012(b). “Donor conception – patients and treatments”. <http://www.hfea.gov.uk/donor-conception-treatments.html> (visited 6/10/2014).

Human Fertilisation and Embryology Authority. 2014(d). “If you were conceived on or after 1 April 2005”.

<http://www.hfea.gov.uk/5526.html> (visited 21/10/2014).

Human Fertilisation and Embryology Authority. 2014(f). “Latest donation figures: Egg and sperm donation in the UK 2012-2013”.

<http://www.hfea.gov.uk/9370.html> (visited 17/5/2015).

Human Fertilisation and Embryology Authority (g). “Statistics on sperm donor demographics 1994-5 and 2004-5”.

<http://www.hfea.gov.uk/docs/Graphs_showing_demographics_of_sperm_donors.pdf> (visited 18/5/2015).

Human Fertilisation and Embryology Authority. 2014(h). *“Code of Practice: 8th Edition (R.7), Section 8 and 20”*. HFEA: London.

<http://www.hfea.gov.uk/docs/HFEA_Code_of_Practice_Oct-2014_-_complete.pdf> (visited 8/7/2015).

Human Fertilisation and Embryology Authority. 2015. “Support and intermediary service”.

<http://www.hfea.gov.uk/9757.html> (visited 1/7/2015).

Human Rights Act 1998(a): Schedule 1, Part 1. HMSO: London.

<http://www.legislation.gov.uk/ukpga/1998/42/schedule/1> (visited 16/10/2014).

Human Rights Act 1998(b): Schedule 1, Part 1, Article 8. HMSO: London.

<http://www.legislation.gov.uk/ukpga/1998/42/schedule/1/part/I/chapter/7> (visited 2/7/2015).

Jadva, V., Freeman, F., Kramer, W., Golombok, S. 2010. “Experiences of offspring searching for and contacting their donor siblings and donor”, *Reproductive Biomedicine Online*, **20**, pp.523-532. <https://www.donorsiblingregistry.com/sites/default/files/images/docs/Offsprings_Experiences.pdf> (visited 29/6/2015).

Jadva, V., Freeman, T., Kramer, W., Golombok, S. 2011. “Sperm and oocyte donors’ experiences of anonymous donation and subsequent contact with their donor offspring”, *Human Reproduction*, **26**, 3, pp.638-645.

<http://humrep.oxfordjournals.org/content/26/3/638.full.pdf+html> (visited 1/10/2014).

Janssens, P., Simons, A., van Kooij, R., Blokzijl, E., Dunselman, G. 2006. “A new Dutch law regulating provision of identifying information of donors to offspring: background, content and impact”, *Human Reproduction,* **21**, 4, pp.852-856. <http://humrep.oxfordjournals.org/content/21/4/852.full.pdf+html> (visited 2/7/2015).

Joint Committee on the Human Tissue and Embryo (Draft) Bill, First Report: Chapter 7, Part 3 and 4. 2007. The Stationary Office: London. <http://www.publications.parliament.uk/pa/jt200607/jtselect/jtembryos/169/16910.htm#a79> (visited 6/7/2015).

Joint Committee on Human Rights. 2008. *“Legislative Scrutiny”*. The Stationary Office: London. <http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/81/81.pdf> (visited 29/6/2015).

Lalos, A., Gottlieb, C., Lalos, O. 2007. “Legislated right for donor insemination children to know their genetic origins: A study of parental thinking”, *Human Reproduction*, **22**, 6, pp.1759-68.

<http://humrep.oxfordjournals.org/content/22/6/1759.full.pdf+html> (visited 15/6/2015).

Lycett, E., Daniels, K., Curson, R., Chir, M., Golombok, S. 2004. “Offspring created as a result of donor insemination: a study of family relationships, child adjustment and disclosure” *Fertility and Sterility*, **82**, 1, pp.172-179.

<http://www.fertstert.org/article/S0015-0282(04)00528-X/pdf> (visited 27/5/2015).

Mroz, J. 2011. “One sperm donor, 150 offspring”, *The New York Times*. 5th September.

<http://www.nytimes.com/2011/09/06/health/06donor.html?_r=0> (visited 29/6/2015).

Nachtigall, R., Tschann, J., Quiroga, S., Pitcher, L., Becker, G. 1997. “Stigma, disclosure, and family functioning among parents of children conceived through donor insemination”, *Fertility and Sterility*, **68**, 1, pp.83-9.

<http://www.fertstert.org/article/S0015-0282(97)81480-X/pdf> (visited 28/5/2015).

NGDT. 2012. “Counselling”, National Gamete Donation Trust.

<http://www.ngdt.co.uk/counselling> (visited 8/7/2015).

NHS. 2014. “Infertility”, NHS Choices.

<http://www.nhs.uk/conditions/infertility/Pages/Introduction.aspx> (visited 15/9/2014).

O’Donovan, K. 1988. “A right to know one’s parentage?”, *International Journal of Law, Policy and Family*, **2**, 1, pp.27-45.

<https://journalarchives-jisc-ac-uk.stmarys.idm.oclc.org/media/pdf/oup/journals/lawfam/lawfam_2_1.pdf/27.pdf> (visited 4/6/2015).

Pennings, G. 1996. “Partner consent for sperm donation”, *Human Reproduction*, **11**, 5, pp.1132-1137.

<http://www.humrep.oxfordjournals.org/content/11/5/1132.full.pdf> (visited 29/6/2015).

Re C (art 8 order: grandparents’ application for leave) [2003] NIFam 13 Family Division.

<http://www.lexisnexis.com.stmarys.idm.oclc.org/uk/legal/results/enhnonsearch.do?ersKey=23_T22286981716&format=GNBFULL&startDocNo=0&resultsUrlKey=0_T22286981717&backKey=20_T22286960518&bct=A&csi=306789&docNo=4> (visited 6/7/2015).

Re Gun-Russo v Nugent Care Society and another [2001] EWHC Admin 556.

<http://www.lexisnexis.com.stmarys.idm.oclc.org/uk/legal/results/enhdocview.do?docLinkInd=true&ersKey=23_T22287995594&format=GNBFULL&startDocNo=0&resultsUrlKey=0_T22288000903&backKey=20_T22288000904&csi=274662&docNo=1&scrollToPosition=0> (visited 6/7/2015).

Re R (on the application of Rose and another) v Secretary of State for Health and another [2002] 3 FCR 731.

<http://www.lexisnexis.com.stmarys.idm.oclc.org/uk/legal/search/enhRunRemoteLink.do?lexisReco=true&A=0.7748784087203576&bct=A&service=citation&linkInfo=F%23GB%23FCR%23VOL%253%25PAGE%25731%25YEAR%252002%25&langcountry=GB&ersKey=23_T22273867916&backKey=null&recommendsType=LexisRecoCitationSuggestions&lexisReco=true> (visited 2/7/2015).

Re W (A minor)(Contact: Application by Grandparent) [1997] 2 FCR 643.

<http://www.lexisnexis.com.stmarys.idm.oclc.org/uk/legal/results/enhnonsearch.do?ersKey=23_T22287068037&format=GNBFULL&startDocNo=0&resultsUrlKey=0_T22287068038&backKey=20_T22287065797&bct=A&csi=274607&docNo=2> (visited 6/7/2015).

Re X (Adopted child: Access to Court File) [2014] EWFC 33.

<http://www.lexisnexis.com.stmarys.idm.oclc.org/uk/legal/results/enhnonsearch.do?docLinkInd=true&ersKey=23_T22287925625&format=GNBFULL&startDocNo=0&resultsUrlKey=0_T22287925626&backKey=20_T22287925627&bct=A&csi=316762&docNo=1&scrollToPosition=0> (visited 6/7/2015).

RTC. 2013. “Factsheet 7: Access to information”, *Reproductive Technology Council.*

<http://www.rtc.org.au/donor/docs/7-Access-to-information.pdf> (visited 2/7/2015).

Rumball, A., Adair, V. 1999. “Telling the story: parents scripts’ for donor offspring”, *Human Reproduction,* **14**, 5, pp.1392-1399.

<http://humrep.oxfordjournals.org/content/14/5/1392.full.pdf+html> (visited 21/5/2015).

Shenfield, F. 1994. “Filiation in assisted reproduction: potential conflicts and legal implications”, *Human Reproduction,* **9**, 7, pp.1348-1354.

<https://journalarchives-jisc-ac-uk.stmarys.idm.oclc.org/media/pdf/oup/journals/humrep/humrep_9_7.pdf/9-7-1348.pdf> (visited 15/6/2015).

Shenfield, F., Steel, S. 1997. “What are the effects of anonymity and secrecy on the welfare of the child in gamete donation?”, *Human Reproduction,* **12**, 2, pp392-395.

<http://humrep.oxfordjournals.org/content/12/2/392.full.pdf+html> (visited 15/6/2015).

Siegels, S., Dittrich, R., Vollmann, J. 2008. “Ethical Opinions and Personal Attitudes of Young Adults Conceived by In Vitro Fertilisation”, *Journal of Medical Ethics*, 34, 4, pp.236-240.

<http://jme.bmj.com.stmarys.idm.oclc.org/content/34/4/236.full.pdf+html> (visited 15/5/2015).

Smart, C. 2010. “Law and the Regulation of Family Secrets”, *International Journal of Law, Policy and Family*, **24**, 3, pp.397-413.

<http://www.lexisnexis.com.stmarys.idm.oclc.org/uk/legal/results/enhdocview.do?docLinkInd=true&ersKey=23_T22333248030&format=GNBFULL&startDocNo=0&resultsUrlKey=0_T22333248038&backKey=20_T22333248039&csi=302251&docNo=2&scrollToPosition=0> (visited 21/9/2014).

SNCME. 2013. “Assisted reproduction – ethical aspects: summary of a report”, *The Swedish National Council on Medical Ethics*.

<http://www.smer.se/wp-content/uploads/2013/03/Slutversion-sammanfattning-eng-Assisted-reproduction.pdf> (visited 2/7/2015).

The Free Dictionary. 2015. “Donor”

<http://www.thefreedictionary.com/donor> (visited 6/7/2015).

Turkmendag, I., Dingwall, R., Murphy, T., 2008. “The removal of donor anonymity in the UK: the silencing of claims by would-be parents”, *International Journal of Law, Policy and Family*, **22**, 3, pp.283-232.

<http://www.lexisnexis.com.stmarys.idm.oclc.org/uk/legal/results/enhdocview.do?docLinkInd=true&ersKey=23_T22321081633&format=GNBFULL&startDocNo=1&resultsUrlKey=0_T22321085658&backKey=20_T22321085659&csi=302251&docNo=2&scrollToPosition=120> (visited 15/6/2015).

United Nations’ Convention on the Rights of the Child 1989.

<http://www.un.org/documents/ga/res/44/a44r025.htm> (visited 16/10/2014).

Vanfraussen, K., Ponjaert-Kristoffersen, I., Brewaeys, A. 2001. “An attempt to reconstruct children’s donor concept: a comparison between children’s and lesbian parents’ attitudes towards donor anonymity”, *Human Reproduction,* **16**, 9, pp.2019-2025.

<http://humrep.oxfordjournals.org/content/16/9/2019.full.pdf+html> (visited 21/5/2015).

Wallbank, J. 2004. “The role of rights and utility in instituting a child’s right to know her genetic history”, *Social and Legal Studies*, **13**, 2, pp.245-264.

<http://sls.sagepub.com.stmarys.idm.oclc.org/content/13/2/245.full.pdf+html> (visited 28/5/2015).

Warnock, M. 1984. “Report of the Committee of Inquiry into Human Fertilisation and Embryology”, Cmnd 9314, Department of Health & Social Security: HMSO.

<http://www.hfea.gov.uk/docs/Warnock_Report_of_the_Committee_of_Inquiry_into_Human_Fertilisation_and_Embryology_1984.pdf> (visited 16/10/2014).